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An Introduction to Developmental Disabilities

*A Resource Guide for Emergency Room Personnel, including
Emergency Room Physicians and Nurses,
Emergency Medical Technicians and
Other Health Care Professionals*

**Funded through a grant from the
Massachusetts Developmental Disabilities Council
August 1997**

**Prepared by Horace Mann Educational Associates, Inc.
101 Constitution Blvd., Unit B
Franklin, MA 02038**

**Elisa Benedetti, RN
Kathy McNeil**

ACKNOWLEDGMENTS

The authors would like to gratefully acknowledge the following for their feedback and assistance in developing this curriculum guide.

Project Advisory Committee Members:

Maureen Boiros, RN, Co-Operative Production, Inc.

Jane Silva, MD, Shriver Clinical Services Medical Program

Ann Smith, Evergreen Center

Barbara Bean, HPHC Developmental Consultation Services

Massachusetts Developmental Disabilities Council

Emergency Room Training Task Force:

Ruth Smith, Ph.D., Chair

Carol Walsh, Department of Mental Retardation

Dorothy Upson McCabe, Massachusetts Nurses Association

Joan Vitello, Boston Medical Center

Kathy Carr, Beth Israel Deaconess Medical Center

Maryfran Hughes, Massachusetts General Hospital

Peggy Freedman, Massachusetts Developmental Disabilities Council

Caroline B. Carregal, Massachusetts Medical Society

Jack Hart, Division of Health Care Quality, Department of Public Health

Leslie Kirle, Massachusetts Hospital Association

Peggy Mogan, Brigham and Women's Hospital

Special thanks to:

Mary Ballard, RN

Ann Bateman, MSN, Ed.D.

Kelly Mendall

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CURRICULUM OUTLINE

I. Introduction

II. Statement of Need

III. Objectives

- A. The learner will demonstrate increased understanding of developmental disabilities**
- B. The learner will describe Medical Neurological Disorders that accompany developmental disabilities**
- C. The learner will isolate common problems with usage or delivery of medical services**
- D. The learner will list strategies that may help assess the patient with developmental disabilities**
- E. The learner will identify common modifications which can be made within the Emergency Room (ER) environment to make services more accessible to the person with developmental disabilities**
- F. The learner will demonstrate an understanding of the impact of legal competency status, the Americans with Disabilities Act and state policies impacting on treatment of individuals with developmental disabilities and the roles of mandated reporters**

IV. Appendices



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An Introduction to Developmental Disabilities

***A Resource Guide for Emergency Room Personnel including
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Other Health Care Professionals***

I. Introduction

This curriculum guide is the result of collaborative efforts among health care personnel, developmental disabilities support providers and state funding agencies, with additional input from many individuals with disabilities and their families or advocates. These efforts have been supported through the Massachusetts Developmental Disabilities Council.

The curriculum, which focuses on emergency treatment, is intended to provide health care professionals with an introduction to developmental disabilities, an understanding of the potential impact of disabilities on quality health care, and a useful resource guide for future reference.

Underscoring all information included in this guide is the recognition that each person with developmental disabilities is unique and must be accorded the respect of being treated as an individual. Quality health care services will only be realized if individuals with developmental disabilities are treated as people first, with accommodations made to support their unique needs.

The information and recommendations included in this manual are not comprehensive nor are they intended to be prescriptive. Rather, these suggestions should be treated as the starting point for discussions among health care professionals, people with disabilities, families, advocates and service providers who are all committed to improving the quality of health care services for these individuals. The highest quality health care system can only exist when professionals are trained and sensitized to the issues of people with developmental disabilities, have necessary information about resources at their disposal, and include people with disabilities who use the services in the assessment process.

II. Statement of Need

Although people with developmental disabilities have had an increasingly more visible presence in their home communities over the past three decades, access to and full inclusion in generic community systems of support continue to fall far short of the ideal. For example, individuals with developmental disabilities, family members and support providers continue to report problems when seeking even the most essential medical care. Access, attitudinal barriers, and a lack of supports necessary to obtain optimal care continue to be areas of concern. Such concerns become exacerbated when the person requiring care has multiple disabilities, significant cognitive challenges, or exhibits behaviors that may be disturbing to others.

Emergency Room (ER) staff express concern around issues such as difficulties in communication, inappropriate use of Emergency Room services, and behavioral support problems. They sometimes are unfamiliar with specific syndromes and the possible implications of those conditions for emergency care. Some Emergency Room personnel have reported a vague understanding of the support services for people with developmental disabilities and expressed a lack of experience and training in assessing these individuals.

These difficulties are compounded by pressures to prioritize individual needs so that treatment is given to those most in need in a timely manner. The implications of secondary disabilities and multiple handicaps must be considered when prioritizing individual needs since these factors may increase the level of risk associated with trauma or the sudden onset of severe illness. Many individuals with significant developmental disabilities have multiple and complex special features that require a comprehensive and coordinated approach to management of their health care needs.

Adults and children with mental retardation and other developmental disabilities are also more likely to be victims of physical, emotional, and/or sexual abuse. Emergency Rooms are often the place where such mistreatment is first detected. Knowledgeable staff in this setting may be an important safeguard for those who are most vulnerable.

III. Objectives

A. The learner will demonstrate an increased understanding of developmental disabilities.

1. Definitions

a. Developmental Disabilities

People with developmental disabilities may have one or more of a wide range of diagnoses or conditions. Many conditions can be developmental disabilities if the onset is early and the disability severe enough to interfere with several major life functions.

The term "developmental disability" includes a wide range of disabilities and conditions including: autism, cerebral palsy, seizure disorders, head injury, mental retardation, physical disabilities, chronic mental illness, deafness and hearing impairments, and blindness. It is estimated that there are more than 90,000 people with developmental disabilities living in Massachusetts (Based on 1990 census figures and 1.5% prevalence rate).

Developmental Disabilities

Section 102(5) of the Developmental Disabilities Act of 1994 (P.L. 101-496) defines the term 'developmental disability' as: "a severe, chronic disability of an individual 5 years of age or older that:

- a.) is attributable to mental or physical impairment or combination of mental and physical impairments;
- b.) is manifested before the individual attains age 22;
- c.) is likely to continue indefinitely;
- d.) results in substantial functional limitations in three or more of the following areas of life activity:

- (1) self-care;
- (2) receptive and expressive language;
- (3) learning;
- (4) mobility;
- (5) self-direction;
- (6) capacity for independent living; and
- (7) economic self-sufficiency; and

- e.) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

b. Mental Retardation

Mental Retardation (MR) is by far the largest subgroup of developmental disabilities. In 1992 the American Association on Mental Retardation (AAMR) published its revised definition of mental retardation.

AAMR Definition of Mental Retardation

Mental Retardation refers to a substantial limitation in present functioning which is characterized by significant subaverage intellectual functioning. This exists concurrently with related limitations in two or more of the following applicable adaptive skill areas:

- communication,
- self-care,
- home living,
- social skills,
- community use,
- self-direction,
- health and safety,
- functional academics,
- leisure, and
- work

Manifestations of mental retardation occur before the age of 18.

With the development of this definition, "Mental Retardation has moved from being considered an absolute trait of the individual to the interaction between the individual who has limited intellectual functioning and his or her environments" (Luckasson and Spitalnik, 1994). For the most part, MR is thought of in terms of its effect on the individual involved. Because of the new definition, the field is moving away from classifications of severity such as profound, severe, moderate and mild. Instead, types of MR are being thought of as related to the level of support required by the individual. These include:

- **Intermittent:** Support is on an "as needed" basis, rather than constant support and supervision
- **Limited:** Support is needed for a limited period
- **Extensive:** Support is necessary on a daily basis in one or more life areas and that support is probably not time limited
- **Pervasive:** Support is required in all life areas at all times

Based on the 1990 census, an estimated 6.2 to 7.5 million people in the United States have mental retardation. Prevalence studies identify a range of 2.5 to 3.0 percent of the general population with mental retardation. Mental retardation is 12 times more common than cerebral palsy and 30 times more prevalent than neural tube defects such as spina bifida. It affects 100 times as many people as total blindness (Batshaw & Perret, 1992). In Massachusetts, there are an estimated 85,000 individuals with a diagnosis of mental retardation.

Definitions and fact sheets relating to developmental disabilities are included in the appendix.

B. The learner will describe Medical Neurological Disorders that may exist in this population.

1. Seizure Disorders

Seizure disorders are common, affecting 21% of all individuals with mental retardation and a total of 50% of the people who have the multiple developmental disabilities of mental retardation and cerebral palsy. Seizures are more common in persons with an IQ below 50 (Hauser & Hersforffer, 1990). These individuals with severe cognitive challenges are more likely to have difficulty in achieving seizure control with medications, often requiring the use of one or more anticonvulsants. These medications may present troublesome side effects for the individual.

Genetically linked disorders associated with structural disturbances that produce seizures include inborn errors of metabolism such as PKU, and the lipidoses. Tuberous sclerosis and neurofibromatosis are syndromes associated with the development of abnormal cerebral tissue (Shapiro, Haxby, & Grady 1992). These inherited primary epilepsies usually remit spontaneously in adolescence and early adulthood (Janz, Beck-Mannagetta & Sander, 1992).

Acquired factors such as congenital lesions resulting from prenatal and perinatal injuries are common in people with epilepsy. Partial seizures can be the result of minor focal lesions such as microgyria, proencephalic cysts, and areas of calcification and atrophy. Secondary generalized seizure disorders may be seen as the result of more severe trauma, anoxia, and infections such as toxoplasmosis, cytomegaloviral inclusion disease, rubella, and acquired immunodeficiency syndrome. Head trauma, infectious processes, and brain tumors can produce seizure activity at any stage of the life cycle. In older individuals, cerebrovascular disease such as cerebral venous thrombosis, cerebral ateritis, and scar tissue formed after a stroke all may result in seizure activity. Systemic toxic and metabolic disturbances such as lead poisoning and ketoacidosis can also cause seizures (Shapiro, Haxby, & Grady 1992).

Engel (1992) points out that persons with developmental disabilities have a higher incidence of instability of the brain cells that contribute to seizure activity. The research of Batshaw & Perret (1992) explains that seizures caused by underlying brain lesions may continue indefinitely without medication. They contend that seizures in people with developmental disabilities may become less frequent as the brain matures. There are many conditions that mimic seizures (See handout "Conditions that Mimic Seizures").

2. Cerebral Palsy

Cerebral palsy is a condition caused when the brain is damaged before, during, or after birth. The overall incidence of cerebral palsy ranges from .6 to 2.4 per 1000 persons depending on the study. Spastic cerebral palsy is the most common subtype (Pharoah, Cooke, Rosenbloom, & Cooke, 1987). It is interesting to note that 82% of individuals with cerebral palsy have at least one associated disability, and 42% have three or more associated disabilities. These disabilities include: cognitive disorders (41%), visual impairments (50-92%), hearing impairments (10%), seizure disorders (40%), and orthopedic impairments, as well as behavioral and emotional disorders (Lagergren's Study 1981).

3. Behavioral Disorders

Not all behavioral disorders have a psychiatric basis. If individuals have limited ability to communicate, the only manifestation of a physical ailment may be an alteration in behavior. Many care providers are aware of the subtle signs and symptoms suggesting possible physical illness. It is important to learn to recognize individual signs of altered behavior in order to avoid delays in seeking appropriate medical attention (Rubin, 1987).

Depression may be the cause of sad or agitated mood, sleep disturbance, appetite disturbance, and/or withdrawal. Individuals may also show an onset or increase in self-injurious behavior if an undetected illness or physical complaint is causing pain or discomfort.

4. Hearing Loss and Hearing Impairments

Northern and Downs (1991) report that in the United States, about 22,000 children, or 1%, are born with permanent hearing loss each year. Karchmer (1985) points out that approximately 33% of these children will have one or more disabilities, including disorders of vision, learning disabilities and mental retardation. Hearing loss may be the result of genetic disorders, structural defects, premature birth, complications during the neonatal periods, trauma, intrauterine infection, recurrent ear infections, and antibiotic toxicity. In Massachusetts, the Massachusetts Commission for the Deaf and Hard of Hearing estimates that 22,000 people or 25% of the agency's service users would qualify as developmentally disabled (1990).

5. Visual Impairments

A significant number of people with developmental disabilities may have some sort of visual condition or difficulty, including cataracts, strabismus, and keratoconus. Conjunctivitis and blepharitis, infections of the eye, occur frequently. The Massachusetts Commission for the Blind (MCB) identifies a total of 8,500 or 25% of their registrants with developmental disabilities (1994).

6. Nutritional Disorders

Obesity is found to be a common medical problem in the outpatient population of people with developmental disabilities. This could be caused by an underlying chromosomal abnormality such as Prader-Willi syndrome or Bardet-Biedl syndrome, or medical conditions such as Cushing's syndrome, hypothyroidism, and insulin-secreting tumors. More free choice in independent living situations may contribute to a tendency to over eat. Individuals may benefit from a nutritional assessment, a structured exercise program, and assistance with meal planning in order to maintain a healthy diet and proper intake. Disabilities such as spina bifida may impair mobility but not normal hand skills or oral motor activity, predisposing the individual to inactivity and weight gain. Certain medications, such as phenothiazines and antidepressants can also cause an increase in the appetite (Morse & Roth 1994 pp. 183-184).

According to a study conducted by Similia and Niskanen (1991), up to 25% of individuals with developmental disabilities are underweight. This is more common in individuals with lower cognitive functioning, eating difficulties, and multiple disabilities. Medical problems such as diabetes, endocrine disorders, gastrointestinal disease, infection, and malignancies should be considered if there is unexplained weight loss. Some individuals with developmental disabilities also have disorders of the digestive tract which require tube feedings. People with developmental disabilities and mental health problems such as anorexia or ruminating behaviors may benefit from behavior plans and/or psychiatric intervention.

Certain medications such as stimulants, antidepressants, or medications given for other medical or psychiatric problems may also cause a change in appetite and contribute to the inability to gain weight. In the older individual with developmental disabilities, weight loss due to decreased intake may be caused by dental problems, chewing difficulties, alterations in taste sensation, constipation, and diseases of the gastrointestinal tract. It is important for support providers to monitor individuals on an ongoing basis and document significant weight gain or loss. By recognizing and addressing changes, conditions can be treated in a timely manner and caloric requirements adjusted to meet the needs of the individual.

7. Respiratory Disorders

Respiratory dysfunction in people with developmental disabilities may be caused by many conditions. Contributing factors include: premature birth; low birth weight; neuromuscular disorders such as Duchenne Muscular Dystrophy; Myelodysplasia or spinal cord injury; and scoliosis when secondary to cerebral palsy (Morse & Roth 1994, pp. 353).

Obstructive airway disease has been recognized as a significant problem in children and adults with Down syndrome. Symptoms include snoring, unusual sleeping

positions, fatigue during the day, reappearance of napping, and behavior changes. For individuals experiencing these symptoms, a detailed history should be obtained for evidence of sleep apnea; a physical examination should be performed which includes an assessment of tonsil size; and a prompt referral should be made to an Ear, Nose, and Throat specialist for further evaluation if warranted. Sinusitis commonly occurs and requires aggressive management (Ohio Western 1992). As with the overall population, individuals with developmental disabilities suffer from the more common respiratory problems such as infections, asthma, and other chronic disorders (e.g. Chronic Obstructive Pulmonary Disease). In addition, a disproportionately high number of people with developmental disabilities may have positive Mantoux tests (tests for tuberculosis) due to past histories of institutionalization.

8. Communication Disorders

It is not uncommon for a person with developmental disabilities to have some alteration or limitation of communication. Speech as a primary means of communication can be affected as a result of severe sensory impairment such as deafness, cognitive challenges or physical disabilities which affect the necessary muscular control. Some of the more common factors that affect a person's ability to communicate include:

- **Developmental Apraxia** is a disorder which occurs when the brain circuits responsible for programming the movements necessary to make sound are impaired. Some characteristics of Apraxia are noticeable groping to produce the correct sound and recognition of errors with an effort to correct them.
- **Dysarthria** is a group of speech disorders resulting from disturbances in muscular control. Because there is damage to the central or peripheral nervous system, there is a certain degree of weakness, slowness, and coordination of movements. This is common in people with conditions such as cerebral palsy. Speech can be slow with exaggerated movements and will not be precise.
- **Cranio Facial Abnormalities** can cause a person's speech to be highly unintelligible. Speech difficulties of this nature are the result of structural defects.
- **Cognitive Deficits** are conditions affecting a person's ability to learn. Mental retardation is the primary example of this.
- **Receptive Language Deficits** affect a person's ability to interpret ideas in the conventional forms. These deficits can be the result of a combination of factors, including sensory impairments and specific learning disabilities.
- **Degenerative Diseases** can cause a person to become increasingly unintelligible.

Types of communication employed by people who do not use conventional speech include American Sign Language, picture, symbol or photograph communication boards/books, computer based systems including voice synthesizer and voice recognition systems, printed words and sentences and Braille.

C.

The learner will isolate common concerns with usage or delivery of medical services.

1. Inappropriate use of Emergency Room services

Most Emergency Rooms are designed for treating injuries and illness requiring prompt interventions. Typical examples of Emergency Room (ER) treatment could include patients experiencing chest pain, a serious bone fracture or multiple trauma as a result of accident. Individuals with disabilities and their family members and support providers oftentimes find it difficult to get medical care when they need it. Unfortunately, in many cases the first and primary source of health care is the local hospital Emergency Room.

There are approximately 90,000 children and adults with developmental disabilities living in Massachusetts. All 90,000 are potential patients of local community emergency services. The Department of Mental Retardation (DMR) estimates that there are 85,000 individuals with mental retardation who live in Massachusetts of whom 27,000 currently receive services funded by DMR. Other state agencies which support people with developmental disabilities in the community include Massachusetts Commission for the Blind (8,500) and Massachusetts Commission for the Deaf and Hard of Hearing (22,000). The Massachusetts Rehabilitation Commission funds supports for a number of adults with severe physical disabilities, and the Department of Social Services oversees non-educational services for children with disabilities. The Department of Public Health, Division of Children and Special Health Care Needs, funds supports for children with complex medical needs.

2. Communication

Effective communication with the patient with developmental disabilities is essential to the health assessment process and to insuring quality treatment. Direct communication with the patient with developmental disabilities may present challenges for Emergency Room personnel. In the case of a person who arrives alone, staff may need to try a variety of approaches to determine the best means of communication. If the individual does not appear to understand or have the ability to respond to oral questions, staff could follow up by presenting simple written questions or lists, asking the person to write their information, checking to determine if he or she has a communication board/book or uses sign language.

Emergency Room personnel may also experience communication difficulties if they address an accompanying support provider only. While a support provider may be able to furnish much of the information required, it is necessary to recognize and address the individual seeking services as well. The patient has first hand information which cannot be conveyed by anyone else. Support providers, the individual seeking services, and medical personnel should all interact during the assessment procedure.

Emergency Room personnel should develop an awareness of the language they use when writing about or speaking with people with developmental disabilities. It is important that language reflects respect for the individual. This can be accomplished simply by speaking of the person first and not their disability.

3. Inadequate Information Provided

Concerns have been expressed by Emergency Room personnel when support providers fail to submit medical packets with current and pertinent medical information. For example, many individuals have multiple medications for conditions ranging from allergies to seizure disorders. To facilitate the assessment process and prevent delays in diagnosis, medical packets should contain chronic presenting conditions, information about current medications, up to date insurance information, and health care proxy documentation if applicable, in a concise and accessible manner. A sample Patient Specific Information Packet is included in the appendix.

4. Behavior Management

Individual profiles detailing possible responses to difficult situations may be included in the Patient Specific Information Packet. Emergency Room personnel should be alerted to the potential of difficulty for those individuals who may express anxiety and fear through aggression or self-injury. Support providers should be consulted to identify reinforcers to facilitate prompt assessment of the individual. Suggestions may include modifying the environment, explaining procedures, and modeling positive verbal and tactile reinforcers. For example, an individual may be calmed by music, may require physical prompts to lie on the examination table, or may respond to support and reassurance. Emergency Room personnel should inform the patient of each phase of the examination, and should begin with the most necessary procedures in case the individual is unable to continue with the examination.

5. Knowledge of Syndromes and Responses to Pain

Support providers should review specific psychological status, chronic health concerns and congenital conditions outlined in the packets with Emergency Room personnel. This will provide a quick and accurate understanding of the individual and facilitate the examination and subsequent diagnosis. For example, the individual may have sensory disorders and respond in a variety of ways to pain. Certain individuals may express pain by rocking, ear pulling or head banging. Biersdorff (1994) points out that an absence of basic pain behaviors when an injury or illness is typically painful suggests that the experience of pain may be significantly altered. An increased pain threshold was noted in 25% of 123 people surveyed who had developmental disabilities. This increased tolerance to pain can be misleading and result in misdiagnosis especially with regard to bone fractures. Long standing medical and/or neurological conditions may mask current presenting problems or may require additional intervention.

6. Prolonged Waiting

Support providers who know the person with a developmental disability best should try to think of ways to help occupy time. Support providers should utilize recreational areas in an attempt to keep the individual calm and engaged while waiting. It is important for Emergency Room personnel to understand the extent to which the individual's functioning has been impaired in order to comprehend their unique developmental level. It should be expected that more time will be required to examine the individual based on their level of communicative, social, motor, and adaptive skills.

When a patient with developmental disabilities arrives at the Emergency Room alone, it may be helpful to assign a staff person to monitor periodically during the waiting period. Depending upon the needs of the individual, setting them up to wait in an exam room rather than the large waiting area may be more effective. The staff person should inform the patient of the steps in their assessment/treatment process and of how long it will be before they are seen. Making a point to provide frequent updates and quick, reassuring contact should help the patient deal more effectively with waiting.

7. Discharge Planning

In some large hospital Emergency Rooms, a specific staff member may be designated as discharge planner while in smaller community hospitals the treating physician and nursing staff would fulfill that responsibility. In either case, it is important for the health care provider to learn as much as possible about the patient and the situation in which the individual lives. Frequently assumptions are made about the types of support which are available to people with developmental disabilities which do not reflect the reality of their lives. Living arrangements of people with developmental disabilities vary, and could include: living in a home funded through DMR which has no access to nursing services and only one direct support staff to assist four people; living independently and receiving intermittent assistance from a case manager; and relying on personal care attendants to assist with daily living activities. Environmental factors such as second floor bedrooms or baths may also pose problems in group living settings where less flexibility is possible than in a family setting.

It may not be possible for the patient to receive the type of assistance needed to carry out discharge instructions without additional supports. This information is necessary in determining if the type of follow up care recommended by the physician can be provided in the home. In some cases, an alternate placement on a temporary basis may be indicated for successful recovery. The physician may also order visiting nurse or home health aide services to monitor progress within the person's home.

Many people with developmental disabilities may be accompanied to the Emergency Room by a family member or paid support staff. These individuals provide support and may help interpret vital information for the person with disabilities. Discharge instructions should be presented in written format in simple language and reviewed

orally with the individual and support person. It is important that an opportunity to ask questions be provided. In cases where the person with disabilities is alone, it is essential that the health care provider follow instructions with questions to determine that the information was understood. The health care provider should inform the individual that they have a personal obligation to indicate if the recommendations are not understood. Emergency Room staff may wish to ask a series of probing questions to insure that the patient understands the instructions.

Upon indicating that they understand the instructions, the individual will sign the discharge instruction sheet. If physically unable to sign, an accompanying support person may do so. The printed discharge instructions should be complete, legible, and easy to understand to ensure better compliance with recommended treatment plans and to avoid return visits to the Emergency Room. Support providers should be prepared to provide accurate documentation for further follow-up within the individual's home.

8. Attitudinal Barriers

In certain social environments such as the Emergency Room, concerns regarding insensitivity toward individuals with developmental disabilities have been expressed by people with disabilities and their support providers. The curriculum is designed to educate support providers and Emergency Room personnel to the unique and individual needs of a person with developmental disabilities in order to ensure an expedient and comprehensive medical evaluation in the Emergency Room.

One objective of this curriculum is to help move our society to the point where an individual's disability status is understood as only one variable in the full range of the human experience. Education is one of the best ways to increase sensitivity to the rights of people with disabilities.

Most of the attitudinal barriers for people with developmental disabilities are the result of misconceptions or stereotypes which were learned, unintentionally, during childhood. Over the years the meanings and usage of all words change. This is the case with words that are used in communicating information and ideas about people with disabilities. Choosing affirmative words and phrases will help establish empowerment, dignity, and respect of individuals with disabilities while simultaneously transforming the personal attitudes of service providers.

D.

The learner will list strategies that may help assess the patient with Developmental Disabilities.

1. Communication and Approach

Performing even routine procedures could present a challenge when assessing a person with developmental disabilities and/or mental retardation. Changes in routine, exposure to medical equipment, and unfamiliar surroundings can produce anxiety. A person who is in pain and unable to fully understand the rationale for specific treatments may experience increased agitation unless care is taken to provide reassurance and support. Leaving a person alone in the examination room should be avoided as this may cause feelings of anxiety, which could be manifested in actions such as increased questioning or vocalizations, crying, wandering from the area in search of support, or self injurious behavior. Prior to the examination, it is important to determine the best approach to use to alleviate a person's anxieties, and assess their understanding of the situation.

When communicating, it is important to keep the individual's cognitive and literacy skills in mind. Assessments should be done in a quiet area free from distractions. To help the patient feel at ease, time should be spent establishing a rapport. To reduce anxiety, the interviewer should face the patient and communicate at eye level (Masterson, 1991). In a calm, unhurried manner, the interviewer should introduce him/herself with a handshake or other culturally appropriate greeting, and address the patient by surname (i.e. Mr. or Ms...). Addressing the patient by name may help them to focus their attention on the interview. It is always acceptable to ask the person how they prefer to be addressed.

To reduce the tendency to give answers that please the interviewer, open ended questions should be used. In some instances however, it may be necessary to ask a series of probing questions to elicit the necessary information. Instructions and explanations should be short, clear, and repeated if necessary (Harper & Wadsworth, 1992). Directions may be better followed if demonstrated first. In cases where this is necessary, an accompanying support provider could be enlisted to demonstrate the action that the health care professional is seeking.

Increased attentiveness on the part of Emergency Room personnel to the individual with developmental disabilities who is alone will most likely result in a successful treatment experience. Any of the identified techniques can be applied to the person who arrives alone. In addition, if the person appears to have a severe disability and require supports, it will be important to seek information about who may be able to provide assistance. If the individual receives any contracted support, there will be a case worker assigned through the funding agency. Probing questions could focus on identifying if the person has a Service Coordinator, Case Coordinator or Social Worker.

2. Respect and Dignity

As with all patients, to protect their dignity, privacy should be provided during interpersonal interactions. To reduce anxiety caused by the fear of losing control, the person should be allowed to have some control over the action or procedure to be performed. The health care provider can make opportunities to give the patient choices in areas where it is possible to be flexible. One possibility might be in the timing of a specific procedure. Allowing control helps the patient preserve a sense of independence, self-worth, and personal dignity. As with all people, if the procedure is painful or uncomfortable, the patient should be informed before it is done. People are better able to deal emotionally and psychologically with discomfort if they are aware of when it is expected to occur.

3. The Role of the Support Provider Accompanying the Person to the Emergency Room

Many people with developmental disabilities will not be able to provide Emergency Room staff with a sufficient medical history due to limitations in cognition or communication. In most cases, these patients will be accompanied to the hospital by a family member/care giver or paid support staff. These individuals can be a valuable source of information and will play a major role in facilitating communication between the patient and the health care provider.

Support providers should identify themselves and be prepared to provide a concise medical history. This history should be included in a Patient Specific Information Packet along with the patient's immunization records, history of childhood illnesses, surgical history, current and over the counter medications, allergies, guardianship status, insurance provider information, and, if applicable, seizure history, menstrual history, and a health care proxy (Minihan & Dean, 1993). The Patient Specific Information Packet can also provide patient specific information such as altered pain behaviors.

Support providers should relay information about the current concerns, including current symptoms and their onset, and the reason for the Emergency Room visit. They should be prepared to provide pertinent phone numbers in the event follow-up is required and to ensure communication with the primary care physician.

Any person with mental retardation who receives supports through DMR has a Health Status Form which includes all relevant information as a part of the Individual Support Plan (ISP). Emergency Room personnel should request to see that form if the person is accompanied by a support provider.

In order to insure the success of the Emergency Room visit, it may be necessary to adjust some typical procedures to accommodate the unique needs of that individual.

The family member or support providers accompanying the patient will be able to help identify the best approach to take.

The accompanying person provides supervision to insure the patient's safety, constant reassurance, and emotional support. They will be able to give suggestions on how to avoid activities which may cause undue anxiety. Simple accommodations such as a separate room or area in which to wait, information about the timing of procedures, communication about plans, permission to move around (if indicated) between treatments, etc., can all help to make the experience less stressful for the patient (Garrard). If the patient is unable to articulate complaints effectively, the ability of the support person to interpret behavioral changes is crucial. They will be able to recognize and respond to subtle signs of discomfort and anxiety, reducing the chance that an escalation of maladaptive behavior will be the patient's only means to communicate that message.

E.

The learner will identify common modifications which can be made within the Emergency Room environment to make services more accessible to the person with developmental disabilities.

While all hospital buildings must be accessible, equipment within those locations may not have been modified. A person with a physical disability may find examination tables inaccessible, call buttons out of reach, and testing procedures and treatment rooms which cannot be accessed without significant assistance from hospital personnel. At a time when one's sense of security is already being shaken by pain, injury, and the necessary examinations by multiple health care professionals, the added indignity of forced dependence on others for increased levels of assistance may represent the "final straw" for many people. These circumstances could result in delayed or less than adequate care for the individual.

Individuals with sensory impairments also require accommodations to the normal operating procedures. Once again, supports which are routinely available during normal business hours may not even be offered on weekends or at night. A person with a severe hearing impairment may miss out on essential treatment and follow up information without the benefit of a sign language interpreter to fully communicate with treating physicians. An individual who is legally blind should be offered the option of having written materials reprinted in large print and/or read aloud with an opportunity to ask follow up questions. Although the person may not directly request such accommodations, the quality of care and overall compliance level with follow up treatment will be much improved if Emergency Room personnel routinely offer simple modifications.

It is not possible to anticipate all of the accommodation needs which might occur, however a number of generic modifications which could benefit a large majority of people can be made very easily if Emergency Room personnel are aware.

These recommendations were derived from an assessment of a sample Emergency Room. The assessment process included a review of the physical site and the sequence of events and situations in each step. Consideration was given to:

- those arriving by ambulance on a stretcher,
- those arriving in their own wheelchairs with a friend or family member,
- and those arriving alone in their own wheelchairs.

Aspects such as mobility issues, spasticity, transfer abilities and weight, communication problems, and strength/weakness were considered. While not all of the following recommendations will apply to any one setting, they may be helpful in planning for individual modifications.

Accommodation vs. Modification

Accommodation appears to be the norm in most Emergency Rooms and some of these recommendations for modifications can be met through staff accommodation as well. These recommendations are designed for setting up the Emergency Room environment in an "as-simple-to-use" way as possible. The recommendations for modifications take into account the critical nature of emergency treatment, the availability of personnel and the need for staff efficiency, as well as the right of a patient with developmental disabilities to have the option of independence while receiving quality care.

Entrance

Electric door openers. Most hospitals and Emergency Rooms have or should have electric door openers as required by the Americans with Disabilities Act (ADA).

Intake

At the sample location, there appeared to be two areas for intake. In one area the immediate information is taken, while the other is where the billing information, doctors name, and other essential data is taken.

Immediate intake

Considerations: It is ideal if the immediate information area is low enough for the individual sitting behind the desk to see a seated individual and vice versa. A seat should be available for those who are too frail or unable to stand even for a short period of time.

Billing intake

Considerations: The billing intake information desk needs to be fully accessible to an individual using a wheelchair, in order for them to sign documents, etc. These details are addressed in the ADA code. Some aspects include the height of the counter, the depth under the countertop (22"), and the width (mm 30").

It will be important to know the best way to retrieve that information from an individual with cognitive or speech deficits; how to briefly and informally quickly test their accuracy (i.e. verification of contradictory information asked in two different ways at two different times); and many other issues for staff approach.

Physically, if the individual has a difficult time signing a document, the staff should ask the patient if they have a signature stamp. In addition, it is important for staff to know where to get in touch with an ASL interpreter, just as they know how to get in touch with a foreign language interpreter. There should be some basic training to the staff regarding patients who may have communication problems or present with communication devices.

Waiting rooms

The waiting room in the sample location had movable chairs. Some individuals who use wheelchairs have complained about the need to sit in the middle of a path of travel when chairs are immovable. Additionally, it is important to remember that for an individual with cognitive problems this can be a very stressful time.

Considerations: As stated in the ADA, either a clear space should be integrated into the seating area or some of the chairs should be movable.

If televisions are available for patients, is the remote control available and therefore accessible?

Are the magazines accessible to an individual with limited range of motion or can they get to them if they use a wheelchair?

Does a staff person physically go to the room periodically to provide reassurance?

Is there a buzzer of some type in the waiting room for an individual with a mobility impairment who may be alone? This should likely be a) wireless or with a long cord, so that the individual can have it within reach and b) a large button for those with poor coordination.

Baseline

One particular, and justified, concern of Emergency Room personnel, is the difficulty in knowing a person's baseline or what is normal for that individual. Is their grimace a normal thing for that individual? Is the limited range of motion in their arm normal or new? What is their pain tolerance? Is their breathing typically shallow? Is this their typical speech pattern and do they have a communication device? Is their comprehension limited to any degree? Do they have any swallowing problems? Are there any positional problems (i.e. cannot lie flat on back)?

Considerations: Emergency Room personnel identify that it would make treatment easier for everyone if people carried an emergency information card along with their insurance information at all times. This type of information would be particularly helpful in the case of someone who may not be able to communicate vital information independently. Emergency information cards could include a brief description of the person and should also include medications, allergies, any significant medical history.

Stretchers

There are several manufacturers of stretchers. At the sample location, Emergency Room staff pointed out that some do not go down very low, such as the Stoker Orthopedic stretchers. On the other hand, the Hastier stretcher went down to 23" from the floor.

Considerations: Be sure that the purchasing agent is aware of the need to choose stretchers that go down to 23" or less, when in their lowest positions. This will ease transfers from wheelchairs to stretchers for the staff.

Transfers

The assessment process focused discussion on the problems that may arise when transferring an individual from their wheelchair to a stretcher, especially with the individual who normally uses a lift at home. Staff at the sample Emergency Room reported that there is a Hoyer lift around, however, in addition to the fact that it generally needs to be tracked down, it was felt that it is just as difficult to get the sling under the patient as it is to use a 2-3 person lift. Often, it is reported, the EMTs are handy, and using staff is much faster and more efficient.

Considerations:

Lifts:

If an Emergency Room decides on a lift, it should be devoted to the Emergency Room or always stationed in the area even if shared with an adjoining department such as Radiology. Ceiling mounted lifts are available. Once tracks are installed in each of several cubicles, a portable lift can be hooked into the track in the cubicle where it is needed.

Slings for lifts:

To eliminate the need to get a sling under a patient, a lift such as the HandiMove could be used, as it has one type of body support that holds the patient around their chest and under their legs, but does not need to be positioned under their buttocks. This, however, could cause problems with an individual who may have broken some ribs. Alternately, there is a "split" sling available from HandiMove and others, that gets tucked down behind someone's back, with two separate "wings" that wrap around the legs.

Wheelchairs

People who use wheelchairs for mobility may arrive at the Emergency Room without their chairs if they have been transported to the hospital by ambulance. As a general rule, there is not enough room in an ambulance to hold anything but the patient. In these cases, Emergency Room personnel should be sensitive to the fact that the individual's mobility will be restricted and offer accommodations such as a portable wheelchair or stretcher.

Considerations: Once an individual is out of his/her wheelchair, it is important that it be physically identified as that person's possession (an extra hospital ID bracelet attached to a post?) and that it stay with the individual when/if they are transferred to another unit. It is equally important that no parts of the chair, straps, splints, cushions, etc. get misplaced. Patients have often had to wait months for some parts and funding for replacement parts appears to be getting more and more difficult to secure. If a patient is going to be out of a powered chair for an extended amount of time, the staff should ask if the wheelchair needs to be plugged in to recharge or to retain its charge.

Call bells

These are pull-cords, that appeared to require a fair amount of pull.

Considerations: Recommended is a light touch push-pad. These could be used by most individuals, some requiring that they be placed beside their heads while some may use a fist or even a foot to activate it. The purchasing department at the sample hospital identified the manufacturer (Dukane) that they use, and when contacted, Dukane identified that there are, in fact, several other switches available including a sip/puff. For hospitals that have pull cords, the "back box" on the wall in the cubicle must be replaced to accommodate these types of switches. Because of the many styles available, it appears to be a good modification. Additionally, if possible, a bright color on the button would be helpful for many, especially in view of the fact that many things in the room at the sample location appeared to be black, white or silver.

Telephones/TDD'S

Telephones may be used by the individuals to contact family members or friends. The sample site allows patients to use the phone at the nurses desk. However this is a problem if the patient is hooked up to IVs or EKGs and cannot access that space.

Considerations:

- 1) A telephone jack in each cubicle would allow use of a telephone or a TDD when the individual cannot get out to the desk
- 2) Rather than having a staff person stand and hold a receiver, both for privacy and for staff time, a couple of small items are recommended.
 - a) a phone cuff (cost under \$10) and would allow an individual with a weak grasp to hold a receiver. This could easily be put on or off the handset as needed.
 - b) a headset would be useful for someone without fine motor control. This could be plugged into the phone only when needed.
- 3) A TDD should be in every Emergency Room. This can also be used as an effective communication device for an individual with a loss or diminished hearing, if the nurse or doctor is a fast typist.

Water

Staff at the sample site report some medical conditions might rule out water, and thus, they do not normally leave water with any of the patients, but instead, assist anyone on an as-needed basis. Other patients may have difficulty swallowing liquids or medications.

Considerations: It may be helpful to have a thickening substance behind the desk for use when necessary to take medications with water (this may already be standard).

Changing rooms

Because the imaging rooms are often associated with the Emergency Room area, it is important that the various tasks done by an individual in this space be considered.

Considerations:

Changing rooms: The doors, interior size, benches, grab bars, call bells, etc. all should suit ADA code.

Lockers: Consideration should be given to the location and heights of hooks in the lockers.

Bathroom

At the sample site, as at many hospitals, the bathroom door was quite heavy to pull open.

Considerations: On a bathroom door or any other door in a room that patients may be exiting by themselves (i.e. changing room), be sure that the weight is low enough or that there is a simple doorbell inside and near the door that goes to a nearby desk, to alert of the need for assistance to get out.

Scales

One other issue discussed was the fact that many individuals who use wheelchairs tend to come to the Emergency Room to be weighed.

Considerations: There are, of course, scales on the market to weigh a chair and its user. One "economy" style is very reasonable, at under \$200.00. Research should identify several more and of improved quality.

F. The learner will demonstrate an understanding of the federal and state regulations, legal competency status and reporting policies which impact on the treatment of people with developmental disabilities.

1. Legal Competency

Legal competency is an issue which needs to be fully explored when a person with developmental disabilities seeks medical treatment. Unfortunately, many family members and support providers do not fully understand the intricacies of guardianship and may unknowingly provide inaccurate information to health care providers. It is essential that emergency medical personnel have an understanding of the legal competency status of a person with developmental disabilities who is seeking emergency medical treatment.

Personal autonomy is central to the idea of adulthood and citizenship. The right to make life decisions and the right not to be under the control of another individual must be guarded. The decision to appoint a legal guardian is based on the risk of substantial harm to a person unless someone assumes decision making responsibility in one or more areas of that person's life.

Guardianship is not to be used to protect the person from the normal daily risks we all face in working, having a residence, moving about, being consumers or associating with others. It should not be used because a person has made or is about to make a poor or harmful decision, has trouble sticking to a decision or relies heavily on other people for advice. If this were the case, we would all find ourselves under guardianship at some point in our lives!

Guardians are appointed by the Probate Court. The court requires evidence that a person is unable to handle personal and/or financial affairs (is incapable of making informed decisions). For individuals with mental retardation, the court also requires evidence of unreasonable risk to their health, welfare or property if a guardian is not appointed, and evidence that a conservatorship (appointing someone to assist with financial decisions only) would not eliminate this risk.

There are several types of legal guardianships. These vary in the degree of decision making power the guardian would have concerning an individual's personal and financial affairs. In all cases, advocates recommend that the least restrictive option possible be considered. A fact sheet describing the types of legal guardianship is included in the appendix.

2. The Americans with Disabilities Act

Under the federal 'Americans with Disabilities Act' and the Massachusetts General Law Chapter 151B, individuals with disabilities have the right to reasonable accommodations for their disability. It is the responsibility of the individual to make the request and identify what accommodations are needed and, unless those accommodations would impose an "undue hardship" on the person or organization providing the service, the requested changes should be made. Any public facility that receives state or federal funding is required to make reasonable accommodations for a disability. This includes most hospitals, schools, and government agencies which are therefore required to make the effort for their services to be as accessible to an individual with disabilities as to those without.

Scheduled doctors' visits and hospital testing can be made accessible for an individual with disabilities if the need for accommodations is made known to the doctor and testing facility in advance. In cases of medical emergencies, when advance notice is impossible, Emergency Room staff are often unaware and unprepared to accommodate the needs of individuals with disabilities. Sensitivity and interaction training is very important, especially for interacting with individuals who have hearing or visual impairments, lack motor control, or have cognitive impairments.

3. Advance Directives

Massachusetts and federal law give every competent adult, 18 years or older, the right to make their own health care decisions, including the right to decide what medical care or treatment to accept, reject, or discontinue. A health care proxy or advanced health care directive is a legal document that allows a competent individual (known as the "Principal") to designate another individual (known as the "Agent") to make health care decisions on their behalf in the event that the Principal becomes unable to make or communicate such decisions in the future. The proxy only becomes effective when the Principal is unable to make informed health care decisions. The Principal's physician makes this determination.

A health care proxy allows a competent individual to communicate their wishes and important choices regarding medical treatment should they later be unable to do so for any reason, whether due to dementia, unconsciousness or coma. Executing a proxy eliminates the need for the appointment of a guardian and substituted judgment determinations before a probate court.

In cases where a person has been adjudicated incompetent or if there is a question about the individual's ability to give informed consent, other guidelines may apply. For example, the Department of Mental Retardation has a detailed policy relating to the provision of life sustaining treatment for people in its care or in the care of provider organizations. The policy affirms that it is a denial of basic human rights and is clearly discriminatory to withhold medical treatment from a person with mental retardation, if

such treatment would be given as a matter of course to a non-disabled individual who has the same physical ailment.

Health care providers should first determine if the patient has a legal guardian by interviewing the individual and any accompanying family member or support provider. It is important to note that a parent who is primary caretaker of an adult child with mental retardation may believe that they are legal guardian, when in fact there is no legal relationship and the individual may be presumed competent. In situations where a person's ability to give informed consent to treatment is in question, it is advisable for health care providers to contact the hospital social service and/or legal departments for guidance and assistance in determining the legal status.

4. Reporting suspected abuse or neglect

Research indicates that both children and adults with developmental disabilities are more likely to be vulnerable to abuse and mistreatment. In Massachusetts three state agencies share the mandate of protecting the rights of people with developmental disabilities.

- 1) The Disabled Person's Protection Commission (DPPC) is the state agency which protects the rights of disabled persons between the ages of 18 and 59. DPPC defines abuse as a serious physical or emotional injury to a disabled person which results from an act or omission, including unconsented sexual activity.
- 2) The Department of Social Services (DSS) is responsible for protecting the rights of all children under the age of 18.
- 3) The Executive Office of Elder Affairs (EOEA) protects people aged 60 and older.

Many people with developmental disabilities will experience some form of abuse or sexual assault, some will suffer significant physical injury, and many will suffer social and emotional harm (Sobsey and Varnhagen, 1989).

"Unfortunately, for children with severe disabilities, discovery of their abuse is usually dependent upon the emergence of incontrovertible physical signs (e.g., death, pregnancy, venereal disease, physical injury) and/or obvious behavioral signs (e.g., sudden changes in behavior that re-enact the abuse). Less obvious behavioral signs do not necessarily alert the untrained caregivers to possible abuse. Even more problematic is that professionals providing services to children with disabilities have too often attributed clear signs of abuse to a disability. This oversight has left children in abusive situations, in some cases for several years." (ARCH Factsheet Number 36, Sept. 1994)

A study by the National Center on Child Abuse and Neglect released in November, 1993, found that the rate of incidence of abuse among children with disabilities is approximately twice the rate of children without disabilities, sexual abuse is at nearly

twice the rate, and emotional neglect is at almost three times the rate (Futurity, Nov. 1993). Other studies document an even higher incidence of abuse for children with disabilities of between four to ten times that of the general population (ARCH Factsheet Number 36, Sept. 1994).

The signs of abuse characteristic of children in the general population are pertinent to children with disabilities. These signs include the following:

- physical injuries, including unexplained bruises, welts, broken bones, burns
- frequent unexplained injuries
- aggressive or withdrawn behavior
- unusual fears
- craving for attention
- wary of physical contact
- afraid to go home
- destructive to self and others
- poor social relations
- fatigue
- lack of concentration
- unusual knowledge of sex

Health care professionals and support providers are mandated reporters who are required by law to report if they have reasonable cause to believe that a disabled person is suffering from a reportable condition of abuse. Reasonable cause is defined as a belief that it is more likely than not that a reportable condition of abuse exists.

The phone numbers and reporting requirements for each agency are included in the appendix.

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APPENDICES

CURRICULUM APPENDICES

- A. Association for Retarded Citizens (ARC) Fact Sheet - Introduction to Mental Retardation**
- B. Child Abuse and Neglect Fact Sheet**
- C. Conditions that Mimic Seizures**
- D. Massachusetts Developmental Disabilities Council (MDDC) Health Policy**
- E. The Disabled Persons Protection Commission (DPPC) Overview**
- F. The Disabled Persons Protection Commission (DPPC) Indicators of Abuse/Neglect**
- G. Family Brochure**
- H. Health Care Proxy/Health Decision Guidelines**
- I. Legal Guardianship**
- J. Massachusetts Network of Information Providers (MNIP) Facts Sheets:
Developmental Disabilities
Autism
Mental Retardation
Cerebral Palsy
Epilepsy
Deaf-Blindness**
- K. Personal Health Fact Sheet**
- L. Special Health Concerns in Persons with Down Syndrome**
- M. States Tables**
 - #7: People per Thousand Who Had a Self Care or Mobility Difficulty, 1990**
 - #8: Children Age 6 to 21 with Specific Learning Disabilities (SLD), Speech or Language Impairments (SLI), Mental Retardation (MR), Serious Emotional Disturbance (SED), Hearing Impairments (HI), and Orthopedic Impairments (OI) Served under Chapter 1 and The Individuals with Disabilities Education Act (IDEA, Part B), 1993-94**
 - #9: Children Age 6 to 21 with Visual Impairments (VI), Autism (A), Deaf-Blindness (DB), Traumatic Brain Injury (TBI), Multiple Disabilities (MD), Other Health Impairments (OHI) Served under Chapter 1 and The Individuals with Disabilities Education Act (IDEA, Part B), 1993-94**
- N. Terminology**
- O. United States Table 1: People with Disabilities, 1991-92**

Introduction to Mental Retardation

What is mental retardation?

According to the new definition by the American Association on Mental Retardation (AAMR), an individual is considered to have mental retardation based on the following three criteria: intellectual functioning level (IQ) is below 70-75; significant limitations exist in two or more adaptive skill areas; and the condition is present from childhood (defined as age 18 or less) (AAMR, 1992).

What are the adaptive skills essential for daily functioning?

Adaptive skill areas are those daily living skills needed to live, work and play in the community. The new definition includes ten adaptive skills: communication, self-care, home living, social skills, leisure, health and safety, self-direction, functional academics, community use and work.

Adaptive skills are assessed in the person's typical environment across all aspects of an individual's life. A person with limits in intellectual functioning who does not have limits in adaptive skill areas may not be diagnosed as having mental retardation.

How many people are affected by mental retardation?

Various studies have been conducted in local communities to determine the prevalence of mental retardation. The Arc reviewed many of these prevalence studies in the early 1980s and concluded that 2.5 to 3 percent of the general population has mental retardation (The Arc, 1982). A recent review of prevalence studies generally confirms this distribution (Fryers, 1993).

Based on the 1990 census, an estimated 6.2 to 7.5 million people have mental retardation. Mental retardation is 12 times more common than cerebral palsy and 30 times more prevalent than neural tube defects such as spina bifida. It affects 100 times as many people as total blindness (Batshaw & Perret, 1992).

Mental retardation cuts across the lines of racial, ethnic, educational, social and economic backgrounds. It can occur in any family. One out of ten American families is directly affected by mental retardation.

How does mental retardation affect individuals?

The effects of mental retardation vary considerably among people, just as the range of abilities varies considerably among people who do not have mental retardation. About 87 percent will be mildly affected and will be only a little slower than average in learning new information and skills. As children, their mental retardation is not readily apparent and may not be identified until they enter school. As adults, many will be able to lead independent lives in the community and will no longer be viewed as having mental retardation.

The remaining 13 percent of people with mental retardation, those with IQs under 50, will have serious limitations in functioning. However, with early intervention, a functional education and appropriate supports as an adult, all can lead satisfying lives in the community.

AAMR's new definition no longer labels individuals according to the categories of mild, moderate, severe and profound mental retardation based on IQ level. Instead, it looks at the intensity and pattern of changing supports needed by an individual over a lifetime.

How is mental retardation diagnosed?

The AAMR process for diagnosing and classifying a person as having mental retardation contains three steps and describes the system of supports a person needs to overcome limits in adaptive skills.

The first step in diagnosis is to have a qualified person give one or more standardized intelligence tests and a standardized adaptive skills test, on an individual basis.

The second step is to describe the person's strengths and weaknesses across four dimensions. The four dimensions are:

1. Intellectual and adaptive behavior skills
2. Psychological/emotional considerations
3. Physical/health/etiological considerations
4. Environmental considerations

Strengths and weaknesses may be determined by formal testing, observations, interviewing key people in the individual's life, interviewing the individual, interacting with the person in his or her daily life or a combination of these approaches.

The third step requires an interdisciplinary team to determine needed supports across the four dimensions. Each support identified is assigned one of four levels of intensity - intermittent, limited, extensive, pervasive.

Intermittent support refers to support on an "as needed basis." An example would be support that is needed in order for a person to find a new job in the event of a job loss. Intermittent support may be needed occasionally by an individual over the lifespan, but not on a continuous daily basis.

Limited support may occur over a limited time span such as during transition from school to work or in time-limited job training. This type of support has a limit on the time that is needed to provide appropriate support for an individual.

Extensive support in a life area is assistance that an individual needs on a daily basis that is not limited by time. This may involve support in the home and/or support in work. Intermittent, limited and extensive supports may not be needed in all life areas for an individual.

Pervasive support refers to constant support across environments and life areas and may include life-sustaining measures. A person requiring pervasive support will need assistance on a daily basis across all life areas.

What does the term "mental age" mean when used to describe the person's functioning?

The term mental age is used in intelligence testing. It means that the individual received the same number of correct responses on a standardized IQ test as the average person of that age in the sample population.

Saying that an older person with mental retardation is like a person of a younger age or has the "mind" or "understanding" of a younger person is incorrect usage of the term. The mental age only refers to the intelligence test score. It does not describe the level and nature of the person's experience and functioning in aspects of community life.

What are the causes of mental retardation?

Mental retardation can be caused by any condition which impairs development of the brain before birth, during birth or in the childhood years. Several hundred causes have been discovered, but in about one-third of the people affected, the cause remains unknown. The three major known causes of mental retardation are Down syndrome, fetal alcohol syndrome and fragile X.

The causes can be categorized as follows:

- Genetic conditions - These result from abnormality of genes inherited from parents, errors when genes combine, or from other disorders of the genes caused during pregnancy by infections, overexposure to x-rays and other factors. Inborn errors of metabolism which may produce mental retardation, such as PKU (phenylketonuria), fall in this category. Chromosomal abnormalities have likewise been related to some forms of mental retardation, such as Down syndrome and fragile X syndrome.
- Problems during pregnancy - Use of alcohol or drugs by the pregnant mother can cause mental retardation. Malnutrition, rubella, glandular disorders and diabetes, cytomegalovirus, and many other illnesses of the mother during pregnancy may result in a child being born with mental retardation. Physical malformations of the brain and HIV infection originating in prenatal life may also result in mental retardation.
- Problems at birth - Although any birth condition of unusual stress may injure the infant's brain, prematurity and low birth weight predict serious problems more often than any other conditions.
- Problems after birth - Childhood diseases such as whooping cough, chicken pox, measles, and Hib disease which may lead to meningitis and encephalitis can damage the brain, as can accidents such as a blow to the head or near drowning. Substances such as lead and mercury can cause irreparable damage to the brain and nervous system.
- Poverty and cultural deprivation - Children in poor families may become mentally retarded because of malnutrition, disease-producing conditions, inadequate medical care and environmental health hazards. Also, children in disadvantaged areas may be deprived of many common cultural and day-to-day experiences provided to other youngsters. Research suggests that such under-stimulation can result in irreversible damage and can serve as a cause of mental retardation.

Can mental retardation be prevented?

During the past 30 years, significant advances in research have prevented many cases of mental retardation. For example, every year in the United States, we prevent:

- 250 cases of mental retardation due to phenylketonuria (PKU) by newborn screening and dietary

treatment;

- 1,000 cases of mental retardation due to congenital hypothyroidism thanks to newborn screening and thyroid hormone replacement therapy,
- 2,000 cases of mental retardation or deafness by use of Rhogam to prevent Rh disease and severe jaundice in newborn infants;
- 3,000 cases of mental retardation due to measles encephalitis thanks to measles vaccine; and
- untold numbers of cases of mental retardation caused by rubella during pregnancy thanks to rubella vaccine (Alexander, 1991).

In addition, with the new vaccine against Hib disease, 3,000 to 4,000 cases of mental retardation can now be prevented.

New attempts at treatment of a variety of causes are being developed. There are now improved ways to manage head trauma, asphyxia (lack of oxygen) and infectious diseases to reduce their adverse effects on the brain. Early intervention programs with high-risk infants and children have shown remarkable results in reducing the predicted incidence of subnormal intellectual functioning.

Finally, early comprehensive prenatal care and preventive measures prior to and during pregnancy increase a woman's chances of preventing mental retardation.

References

AAMR (1992). *Mental Retardation: Definition, Classification, and Systems of Supports*, 9th Edition.

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Batshaw, M. and Perret, Y. (1992). *Children With Disabilities: A Medical Primer*. Baltimore: Paul H. Brookes Publishing Co.

Fryers, T. (1993). Epidemiological Thinking in Mental Retardation: Issues in Taxonomy and Population Frequency. In Bray, N.W., *International Review of Research in Mental Retardation*, Vol. 19. Novato, Calif: Academic Therapy Publications.

The Arc (1982). *The Prevalence of Mental Retardation* (out-of-print).

Where can I go for more information?

For more information about the new definition and classification system for mental retardation, call AAMR at 1-800-424-3688 for phone numbers of the authors who are available to answer specific questions.

Staff at the national headquarters of The Arc can also help you with a variety of other topics related to mental retardation. Or, call your local chapter of The Arc:

The Arc
National Headquarters

Child Abuse and Neglect Fact Sheet

- Child abuse was formally recognized by the medical profession in 1961 as the "battered child syndrome."
- In 1991, state child protective service agencies received and referred for investigation an estimated 1.8 million reports of alleged child abuse and neglect, involving approximately 2.7 million children. Since 1980, reports of child abuse and neglect have more than doubled. (NCANDS, Working Paper 2, 1991 Summary Data Component)
- Approximately 863,000 children were found to be substantiated or indicated victims of child abuse and neglect in 1991. More than three children die each day in the United States as a result of abuse or neglect. (NCANDS, Working Paper 2, 1991 Summary Data Component)
- Among substantiated cases of child maltreatment in 1991, approximately 44 percent were for neglect, 24 percent for physical abuse, 15 percent for sexual abuse, and 17 percent for other forms of maltreatment. (NCANDS, Working Paper 2, 1991 Summary Data Component)
- The link between substance abuse and child abuse has strengthened over the years. Parental abuse of alcohol and use of other drugs has been identified as a major factor contributing to child maltreatment and death. It is estimated that nearly 10 million children under age 18 are affected in some way by the substance abuse of their parents.
- Child maltreatment often has negative short- and long-term effects on children's mental health and development. For example, abused and neglected children frequently suffer drops in IQ and an increase in learning disabilities, depression and drug use.
- The effects of child abuse are sometimes obvious even decades later. The effects are often pervasive: mental, physical and social in nature. Suicide, violence, delinquency, drug and alcohol abuse and other forms of criminality are frequently child abuse-related.
- Studies of adults show that 15 percent to 38 percent of women report experiences of various types of sexual victimization during childhood and adolescence, and about 10 percent of men report sexual abuse during childhood and adolescence.
- Although child abuse occurs in all racial, ethnic, cultural and socioeconomic groups, physical abuse and neglect are more likely among people in poverty. Reflecting the high rates of poverty among ethnic minorities, minority children enter the child protection system in disproportionately large numbers.

For more information, contact the National Clearinghouse on Child Abuse and Neglect Information
P.O. Box 1182 • Washington, DC 20013-1182 • (800) FYI-3366

CONDITIONS THAT MIMIC SEIZURES

Systemic

- Syncope (fainting)
- Breath-holding spells
- Hyperventilation attacks
- Hypoglycemia
- Tetanus
- Gastroesophageal reflux (may manifest as an increase in extensor tone)
- In children with cerebral palsy, as the child tries to assume a position of increased comfort; this may be mistaken for a tonic seizure

Neurological

- Sleep disorders (night terrors, sleepwalking, nightmares, sleep apnea, bruxism, head banging)
- Tics
- Migraine headaches
- Transient ischemic attacks in older individuals or those with hypertensive
- Cardiac disease
- Paroxysmal vertigo
- Tourette syndrome
- Extrapyramidal disorders (e.g., chorea, athetosis)
- Dyskinesias (may be secondary to antipsychotic medications)

Behavioral

- Episodic dyscontrol syndrome (rage attacks)
- Pseudoseizures
- Panic attacks
- Hysteria
- Attention deficit hyperactivity disorder
- Self-stimulatory behaviors (particularly masturbation in children)
- Self-injurious behaviors

Developed by Joyce S. Morse (1993)



Commonwealth of Massachusetts **Massachusetts Developmental Disabilities Council**

*174 Portland Street, 5th Floor
Boston, MA 02114*

HEALTH POLICY

(adopted February 11, 1997)

The Massachusetts Developmental Disabilities Council (MDDC) believes that all people with developmental disabilities must receive quality health care which is individualized to meet their needs, appropriate, and affordable. The Massachusetts Developmental Disabilities Council believes that issues of health care quality must be addressed and prioritized as rapid changes occur in the health care industry from primarily fee for service and indemnity models to one of managed care. Our present concerns with the system include fragmentation between state agencies involved with health care service delivery, differences in eligibility criteria, and categorical differences in who receives and who does not receive services.

We are concerned with all aspects of health care including preventative, health and hygiene, mental health, dental health, and physical health across the age span (from prenatal, childhood, adult, and older health services).

A quality health service delivery system must:

- provide services of the highest quality
- provide services in the most timely and cost effective manner
- address the needs of multicultural people with developmental disabilities
- enhance the self-determination of people with developmental disabilities and stress their dignity
- simplify the process of health care delivery
- simplify administrative paperwork requirements for providers
- promote coordination
- avoid duplication
- use existing information and develop other resources as a basis for decision-making
- provide health care professionals who are trained and sensitized to the issues for persons with developmental disabilities and knowledgeable about access to resources for this population
- promote the participation of people with disabilities in needs assessments and in evaluating the services provided

(617) 727-6374 (Voice)

(617) 727-1885 (TTY)

(617) 727-1174 (FAX)

email: council@mddc.state.ma.us

THE DISABLED PERSONS PROTECTION COMMISSION

99 BEDFORD ST. RM. 200

BOSTON, MA 02111

TO REPORT ABUSE: 1-800-426-9009 V/TTY (24 HOUR HOTLINE)

BUSINESS OFFICE: 617-727-6465 V/TTY (WEEKDAYS 8:45 A.M. - 5:00 P.M.)

DISABLED PERSONS PROTECTION COMMISSION OVERVIEW

The Disabled Persons Protection Commission (DPPC), operating under M.G.L. c. 19C, has as its purpose to "investigate and remediate instances of abuse of disabled persons in the commonwealth." The Commission, similar to the Department of Social Services for children and the Executive Office for Elder Affairs for elders, acts to protect a particularly vulnerable segment of the population: disabled adults between the ages of 18 and 59 years of age who are dependent on another to meet a daily living need, effectively "filling the gap" between the child protection and elder protection systems. The Commission is able, by the terms of its statute, to act independently in investigations and the protection of disabled persons. The DPPC is responsible for the protection of disabled persons in state care and in private settings, and for the investigation of abuse in those settings.

DEFINITIONS

The DPPC statute is contained in chapter 19C of the General Laws. The statute defines a **disabled person** as a person between the ages of 18 and 59, inclusive, who is mentally retarded or otherwise mentally or physically disabled and as a result of the disability is wholly or partially dependent upon others to meet daily living needs.

Abuse is defined as serious physical or emotional injury which results from an act or omission.

A **caretaker** of a disabled person is defined as the person or agency responsible for a disabled person's health or welfare, whether in the same home, a relative's home, a foster home, or any day or residential setting.

REPORTING

Under the law, the Commission receives reports of suspected abuse of disabled adults. Certain individuals who, in their professional capacity have regular contact with disabled persons and therefore are more likely to be aware of abuse, are required to report to the Commission. The professions included in the list of those who are so-called mandated reporters are virtually the same as those who are required to report cases of suspected abuse of children and elderly persons -- medical personnel, police officers, probation officers, dentists, teachers, social worker and psychologists, guidance counselors, and employees of private agencies providing services to disabled persons. Additionally, the statute adds to this list employees of the agencies within the Executive Office of Human Services. If any of these individuals fail to make such a report that person is liable for a fine of up to \$1000. In return for this requirement, however, mandated reporters are immune from any civil or criminal liability as a result of making a report.

All other citizens are encouraged to report to the Commission and are also immune from liability if their report is made in good faith.

The Commission receives reports 24 hours per day through its Hotline at 1-800-426-9009 V/TTY and the business office may be reached during regular business hours at 617-727-6465 V/TTY.

INVESTIGATION

Upon receiving a report, the Commission may investigate itself, or refer the matter to the appropriate state agency for investigation with DPPC monitoring. First, the Commission determines the nature of the alleged abusive situation, depending upon the disability of the allegedly abused person and the identity of the caretaker of that person. When a state agency is the caretaker of the disabled person, the referral is made to that agency. The Commission then monitors the investigation. When the caretaker is not a state agency, the case, if referred, is sent to the Department of Mental Retardation in the case of alleged victims who are mentally retarded, to the Department of Mental Health when the person is otherwise mentally disabled, or to the Massachusetts Rehabilitation Commission when the disabled person is physically disabled.

The Commission must also determine the urgency of the situation. When the case is an emergency, the Commission first acts to end the danger, regardless of the identity of the victim. Once that has occurred, the case is referred for investigation, unless the alleged victim is a child or person 60 years of age or older, in which event the matter is referred to the appropriate agency. When the victim is a disabled adult, an emergency report is referred to the proper agency as described above and within 24 hours that agency is required to complete an investigation and evaluation and, if necessary, provide protective services to the disabled person. When the case is not an emergency the investigation, evaluation, and provision of protective services must be completed within 10 days. The Commission monitors all investigations and receives investigation and evaluation reports from the agency.

Additionally, the Commission may conduct a formal investigation, which includes a hearing, to ascertain the scope of and remedy for an abusive situation.

When the Commission investigation involves a matter which is also the subject of a law enforcement investigation the Commission may delay or defer its investigation. However, the Commission is *required* in such a situation to monitor the law enforcement investigation.

The statute also provides a criminal penalty for persons who discharge, discipline, threaten, or discriminate against anyone who reports to or provides information regarding abuse of a disabled person to the Commission or agencies in the Executive Office of Human Services.

PROTECTIVE SERVICES

The Commission insures, in cases where disabled persons have been abused, that the victim receives the necessary services to provide protection. These may include but are not limited to legal services, location of alternative housing, counseling, respite services, and social service case management. The competent disabled adult may, of course, decline services.

The Commission may, in cases where the disabled person does not have the capacity to consent to the provision of protective services, request that a court decide for the person whether protective services should be provided. The court may appoint a guardian *ad litem* for the person or issue other protective orders.

The Disabled Persons Protection Commission is located at 99 Bedford Street, Room 200, Boston, Massachusetts 02111. Please contact the Commission for further information.

"DPPC IS PROUD TO BE CELEBRATING ITS 10TH ANNIVERSARY!"

DISABLED PERSONS PROTECTION COMMISSION
99 BEDFORD ST. ROOM 200
BOSTON, MA 02111

TO REPORT ABUSE: 1-800-426-9009 V/TTY 24 HR. HOTLINE
BUSINESS OFFICE: 617-727-6465 V/TTY (8:45 A.M. - 5:00 P. M.)

DISABLED PERSONS PROTECTION COMMISSION

INDICATORS OF ABUSE/NEGLECT

INJURIES:

A. Bruises and/or Welts

1. Bilateral bruising eg: top of shoulders, both sides of face, or insides of both thighs.
2. Bruises on several different surface areas eg: bruises reportedly due to bumping into bedrail, while bruises are also present on top of head, inside of thigh or buttocks.
3. Bruises in various stages of healing eg: fresh and faded bruises present.
4. Multiple bruises, or bruises forming patterns or clusters eg: bruising on top of forearms of both arms to elbow.
5. Bruise has the shape/size of a familiar object eg: hand print with finger marks, electric cord, belt buckle.
6. Bruises regularly appear eg: after stress on family, worker visits, on weekends.

B. Burns

1. Scalding burns eg: causing skin blistering from hot water, extent of burns covering body does not fit with explanation of burns.
2. Small burns the shape of cigarette or cigar butts eg: especially on soles of feet, palms, back of buttocks.
3. Burns the shape and size of a familiar object eg: iron, electric burner.

C. Abrasions eg. marks from rope or other restraints, especially on arms, legs, torso.

D. Cuts, Lacerations, Punctures or Wounds.

E. Sprains, Dislocations, Fractures or Broken Bones

F. Internal injuries eg: unexplained reported pain, difficulty with normal functioning of organs, bleeding from body orifices.

G. Sexual Abuse, eg: genital pain or itching, vaginal or anal irritation; bleeding or bruises on external genitalia, vaginal or anal areas, difficulty walking or sitting; torn, stained or bloody underclothing.

NEGLECTFUL CONDITIONS:

A. Victim Conditions

1. Evidence of poor hygiene eg: matted or lice infested hair, soiled clothing, odors or presence of feces/urine, dirty nails/skin.
2. Unclothed, or improperly clothed for weather.

3. Decubiti (bedsores), skin rashes related to unchanged bed, urine soaked linens.
4. Untreated medical or mental conditions, eg: infection, soiled bandages, unattended fractures.
5. Medication mismanagement eg: over-medication or medications are not given at prescribed times.
6. Lacks needed dentures, eyeglasses, hearing aide, walker, wheelchair, braces.
7. Dehydration indicated by low or non-existent intake of fluids, low urinary output; dry fragile skin; dry sore mouth; constipation; apathy or lack of energy and mental confusion.
8. Malnourishment indicated by low, sporadic or non-existent intake of food, apathy, confusion and edema.

B. Living Environment

1. No toilet or commode.
2. Inadequate food storage.
3. Inadequate food.
4. Water unpalatable.
5. Water unavailable.
6. Inadequate heating.
7. Heating system in dangerous, unrepairs or unrepairable condition.
8. Inadequate ventilation/cooling.
9. Inadequate lighting, no electricity.
10. Animal/insect infestation eg; cats, dogs, rats, fleas
11. Crowded living space, eg: disabled person sleeping on sofa in kitchen or living room.
12. Housing structurally unsafe.
13. Fire hazard, eg: faulty wiring, cluttered space so client could not leave dwelling.
14. Inadequate sanitation/substandard cleanliness.
15. Architectural barriers.
16. Hazardous substances, eg: toxic materials.
17. No phone/access to outside help in case of fire or medical emergency.
18. Outdated or unmarked medications are present.
19. Restraining devices are evident.
20. Empty bottles of liquor are present.
21. Frequent moves between residences are made.

NEGLECTFUL ACTIONS:

1. Caretaker fails to wash or bathe disabled person.

2. Caretaker fails to shop, prepare meals or feed disabled person, or meals are missed.
3. Caretaker fails to launder, dress or change disabled person's clothes.
4. Caretaker fails to assist disabled person to toilet or commode.
5. Caretaker fails to administer medications properly.
6. Caretaker fails to change bed pads so bed is soiled and/or urine soaked or to turn disabled person in bed so bedsores/decubiti present.
7. Caretaker has disabled person sleep on sofa, or floor.
8. Caretaker evicted disabled person and/or abandoned.
9. Caretaker mismanages finances, or misappropriates funds eg: for own use.
10. Disabled person is left unsupervised eg: disabled person disoriented and wanders.

EXPLANATIONS OF INJURIES/NEGLECT:

1. Injuries are unexplained or explanation does not fit with the injuries observed.
2. Stories of how injuries happened differ: especially noticeable in separate interviews.
3. A history of similar injuries, and/or hospitalizations are present, eg: numerous falls are reported to have occurred although the disabled person ambulates well.
4. Disabled victim reports abuse/neglect. Although the specific description of abuse or neglect is more believable than a report by a disabled person who forgets, confuses details, rambles and/or is vague, equal attention should be given to both kinds of reports.
5. Caretaker/abuser confesses to having "disciplined" the disabled person in order to control or provide care. Rationalizes behavior.
6. Caretaker/abuser admits to abuse/neglecting disabled person "in the past".
7. Caretaker/abuser admits to abuse/neglect while minimizing extent of, eg: physical contact by stating the disabled person was only "pushed".
8. Disabled victim makes excuses for why he/she is inadequately cared for, minimizing extent of injuries or conditions of neglect.

BEHAVIOR OF CAREGIVER/ABUSER:

1. Is afraid of losing control, having a "nervous breakdown".
2. Is exhausted from caring for disabled person.
3. Is frustrated with not being able to get disabled person to cooperate with care; blames disabled person.
4. Wants to leave disabled person; has little leisure time.
5. Is angry with or resents other relatives for not helping with care of disabled person; blames others for problems.
6. Isolates disabled person from the outside world, friends or relatives.
7. Ignores and does not speak to disabled person; emotionally isolates.

8. Does not touch or comfort the disabled person.
9. Threatens or intimidates the disabled person with physical abuse, withdrawal of care, loss of relationships, desertion, or nursing home or other alternative placement.
10. Speaks for the disabled person; dominates the interview and/or refuses to allow the disabled person to be interviewed alone.
11. Expresses concern for his/her own needs, eg: restriction on lifestyle while caring for disabled person, while ignoring or minimizing importance of the disabled victim's needs. Is unaware of the disabled person's needs.
12. Exhibits signs of alcohol/drug dependence, and impaired functioning related to substance abuse.
13. Is defensive.
14. Denies problem exists, or disabled person is ill despite evidence.
15. Switches the subject abruptly or appears not to hear the interviewer when concerns for the disabled person's welfare are mentioned.
16. Conflicts with spouse or other family members; marital/familial tension is present.
17. Is hostile, agitated and/or volatile.
18. Exhibits poor self-control: is impulsive or reactionary.
19. Has a history of or exhibits bizarre and/or violent behaviors, delusions, irrational or confused thinking, strong mood swings or emotional outbursts.
20. Is concerned with spending too much money.
21. Has unrealistic expectations of disabled person.
22. Is unreasonably dissatisfied with and changes frequently, physicians and/or other service providers.
23. Conflicts with others in the community.
24. Handles the disabled person roughly, pushing or pulling, hitting or slapping.
25. Touches or fondles the disabled person inappropriately, or exhibits other overt sexual behavior toward the disabled person.
26. Curses, screams, insults, and/or calls the disabled person names.
27. Gives glances, stares at, makes non-verbal cues to disabled person to be silent and compliant.
28. Was abused/neglected as a child.
29. Over reacts or demands unusual treatment for a minor problem, and under reacts to a serious problem and refuses treatment for the disabled person.
30. Has a negative attitude toward disabilities.
31. Is intrusive, not allowing the disabled person privacy.
32. Refuses to apply for economic aid or services; resists outside help.
33. Throws objects at the disabled person.
34. Has difficulty hearing, understanding, communicating with the disabled person.

35. Is unemployed.
36. Is emotionally dependent on/attached to the disabled person.

BEHAVIOR OF DISABLED VICTIM:

A. The Disabled Victim

1. Cries easily, frequently.
2. Expresses a desire to die, and/or hopelessness.
3. Talks about the past, and avoids talking about the present, for example the caregiver or holidays.
4. Expresses unrealistic or magical expectations that she/he will receive adequate care or will not be hit again.
5. Is alcohol-dependent, and functioning is impaired by drinking.
6. Exhibits stress-related illness, for example, hypertension, arthritis, congestive heart failure, asthmatic attacks, somatized pain.
7. Has nightmares and difficulty sleeping.
8. Has a sudden loss of appetite, unrelated to medical condition.
9. Has become emotionally numb, withdrawn, and/or detached.
10. Shakes, trembles, and cowers in presence of caregiver/abuser.
11. Exhibits fear of caregiver/abuser, and hesitates to speak while others are in the room.
12. Is hyper alert, vigilant in watching actions of caregiver/abuser.
13. Exhibits an exaggerated startled response to sudden movement.
14. Obsesses, worries or is anxious about his or her own performance for example, being incontinent. Is anxious to please the caretaker.
15. Exhibits distrust of others.
16. Is difficult to care for by reason of emotional outbursts, constant criticism of the caregiver, cursing, hitting or scratching the caregiver.
17. Has suddenly become more dependent on the caregiver, adopting the role of a child.
18. Is dependent on the caregiver for emotional support, affection.
19. Is incontinent, malodorous, unpleasant to be around.
20. Asks to be separated from the caregiver/abuser.
21. Is resistant to taking medication, being bathed, eating and allowing a caregiver to provide care.
22. Has a rapid progression of physical deterioration.
23. Denies problem despite evidence.
24. Speaks of the caregiver in glowing terms, despite apparent abuse/neglect.

**TO REPORT THE ABUSE OF A DISABLED PERSON CALL
THE DISABLED PERSONS PROTECTION COMMISSION
24-HOTLINE 1-800-426-9009 V/TTY**

"DPPC IS PROUD TO BE CELEBRATING ITS 10TH ANNIVERSARY!"



CURRENT MEDICATIONS SUGGESTIONS

Medication	
Dose	
Frequency	
Medication	
Dose	
Frequency	
Medication	
Dose	
Frequency	
Medication	
Dose	
Frequency	

- Try to use the emergency room only in emergencies. If it is not an emergency, arrange to see your primary care physician as soon as possible.
- Be calm.

Introduce yourself and the person seeking services.

Inform emergency room staff of the person's communication style including any limitations.

Inform the emergency room staff of any special needs or concerns they should be aware of.

Ask who will be able to keep you informed throughout the visit.

Make sure you understand discharge instructions and other information. Ask to have information written out legibly and repeated if needed.

Emergency Medical Information for

(Name) _____

prepared by

(Name of Preparer) _____

recorded on

(date) _____

*Prepared by Horace Mann
Educational Associates, Inc.
Through a grant from the
Commonwealth of Massachusetts
Administering Agency for
Developmental Disabilities*

Be Prepared ...

MEDICAL HISTORY

IMMUNIZATIONS

SURGERIES:	
CHILDHOOD ILLNESSES:	
ALLERGIES:	
SEIZURE DISORDER:	
CURRENT WEIGHT:	
OTHER:	

Name	
Address	
Date of Birth	
Social Security Number	
Medical Record Number/Hospital	
Mass Health/Medicaid	
Medicare	
Other Insurance	
Primary Care Physician	Phone
Address	
Primary Care Provider Number	
Considered Competent	<input type="checkbox"/> yes <input type="checkbox"/> no
Legal Guardian	
Address	
Phone	

MASSACHUSETTS HEALTH CARE PROXY

TO MY FAMILY, DOCTORS, AND ALL THOSE CONCERNED WITH MY CARE:

1. Appointment

I, _____, (the Principal),

residing at _____
being a competent adult at least eighteen (18) years of age or older, of sound mind
and under no constraint or undue influence, hereby appoint the following person to
be my **HEALTH CARE AGENT** under the terms of this document:

Name: _____

Address: _____

Telephone(s): _____

In so doing, I intend to create a Health Care Proxy according to Chapter 201D of the
General Laws of Massachusetts. In making this appointment, I am giving my
Health Care Agent the authority to make any and all health care decisions on my
behalf, subject to any limitations I state in this document, in the event that I should
at some future time become incapable of making health care decisions for myself.

2. Alternates (Completion of this section is optional, but recommended)

I hereby appoint the following person or persons in succession to serve as my
Health Care Agent in the event that my former Health Care Agent is not available,
willing or competent to serve, or is disqualified from acting on my behalf. Each
alternate is to act alone and in the order listed.

Alternate 1: _____ Alternate 2: _____

Address: _____ Address: _____

Telephone(s): _____ Telephone(s): _____

(Additional alternates may be named in numbered sequence. Attach additional
pages as needed. Each new page should be signed and dated by the Principal.)

3. Powers Given to Health Care Agent

- a. I give my Health Care Agent full authority to make any and all health care decisions for me including decisions about life-sustaining treatment, subject only to the limitations I state below.
- b. My Health Care Agent shall have authority to act on my behalf only if, when and for so long as a determination has been made that I lack the capacity to make or to communicate health care decisions for myself. This determination shall be made in writing by my attending physician according to accepted standards of medical judgment and the requirements of Chapter 201D of the General Laws of Massachusetts.
- c. The authority of my Health Care Agent shall cease if my attending physician determines that I have regained capacity. The authority of my Health Care Agent shall recommence if I subsequently lose capacity.
- d. I shall be notified of any determination that I lack capacity to make or communicate health care decisions where there is any indication that I am able to comprehend this notice.
- e. My Health Care Agent shall make health care decisions for me only after consultation with my health care providers and after full consideration of acceptable medical alternatives regarding diagnosis, prognosis, treatments and their side effects.
- f. My Health Care Agent shall make health care decisions for me only in accordance with my Health Care Agent's assessment of my wishes, including my religious and moral beliefs, or, if my wishes are unknown, in accordance with my Health Care Agent's assessment of my best interests.
- g. My Health Care Agent shall have the right to receive any and all medical information necessary to make informed decisions regarding my health care, including any and all confidential medical information that I would be entitled to receive.
- h. The decisions made by my Health Care Agent on my behalf shall have the same priority as my decisions would have if I were competent over decisions by any other person, including a person acting pursuant to a Durable Power of Attorney, except for any limitation I state below or a specific Court Order overriding this Health Care Proxy.

- i. If I object to a health care decision made by my Health Care Agent, my decision shall prevail unless it is determined by Court Order that I lack capacity to make health care decisions.
- j. Nothing in this Proxy shall preclude any medical procedure deemed necessary by my attending physician to provide comfort care or pain alleviation including but not limited to treatment with sedatives and painkilling drugs, non-artificial oral feeding, suction, and hygienic care.
- k. (Optional) I specifically limit my Health Care Agent's authority as follows:

(Attach additional pages as needed. Each new page should be signed and dated by the Principal.)

- l. I may revoke this Health Care Proxy by executing a later Health Care Proxy or by notifying my Health Care Agent or health care provider orally or in writing or by any other act showing a specific intent to revoke this Health Care Proxy.

4. Signature of Principal

I hereby sign my name to this Health Care Proxy in the presence of two witnesses.

Signature: _____ Date: _____

{Complete here only if Principal is physically incapable of signing:}

I have signed the Principal's name above at the Principal's direction and in the presence of the Principal and two witnesses:

Name of Signatory: _____

Address of Signatory: _____

5. Witnesses

We, the undersigned, have each witnessed the signing of this document by the Principal or at the direction of the Principal and state that the Principal appears to be at least eighteen (18) years of age, of sound mind and under no constraint or undue influence. Neither of us is named as Health Care Agent or Alternate Health Care Agent in this document.

Witness 1: _____ **Witness 2:** _____

Signature: _____ Signature: _____

Address: _____ Address: _____

_____ _____
Telephone(s): _____ Telephone(s): _____

6. Statement of Health Care Agent and Alternates (Optional)

I have been named by the Principal as the Principal's Health Care Agent or as an Alternate Health Care Agent in this document.

I have read this document carefully and accept the appointment. I have had or plan to have a discussion with the Principal about the Principal's health care wishes.

I am **not** an operator, administrator or employee of a hospital, clinic, nursing home, rest home, Soldiers Home or other facility defined in Section 70E of Chapter 111 of the General Laws of Massachusetts where the principal is presently a patient or resident or has applied for admission, or, if I am an operator or administrator or employee of such a facility, I am also related to the Principal by blood, marriage or adoption.

Health Care Agent: _____

Alternate Health Care Agent 1: _____

Alternate Health Care Agent 2: _____

COPIES OF THIS DOCUMENT SHALL HAVE THE SAME FORCE AND EFFECT AS THE ORIGINAL.

HEALTH DECISION GUIDELINES

1. Has this person ever made life decisions on his/her own? Have the outcomes from these decisions been negative or positive?
2. Has this person ever made surgical or extensive medical decisions? What was his/her response to the treatment and follow up?
3. Does this person have an understanding of his/her own health needs? How accurate is his/her knowledge of their health needs?
4. What kind of medical or dental decisions has this person made? What support was needed? (We don't want to exclude those who can make decisions with help and/or support to various degrees).
5. Does this person understand the risks and benefits of medications he/she takes? (Not rote memorization from a self medication training)
6. Is it likely that this person will benefit from any interventions within the next year?
7. Does this person seek assistance or information when faced with difficult or different choices? Where? How? From 'Whom?
8. Has this person ever given an indication of a preference about how he/she would like to be treated or want to live?
 - a. Have there been circumstances in which avoiding suffering would matter?
 - b. Are there specific religious, ethical or cultural considerations that may affect this person's care?
9. Who would this individual consider his/her best advocate? Who else might be considered?
10. Should a Health Care Proxy be initiated at this time?
11. If a H.C.P. is not indicated, what education and support would assist this individual?

ADVANCE DIRECTIVES

YOUR RIGHT TO MAKE HEALTH CARE DECISIONS

UNDER THE LAW IN MASSACHUSETTS

INTRODUCTION

Massachusetts and federal law give every competent adult, 18 years or older, the right to make their own health care decisions, including the right to decide what medical care or treatment to accept, reject, or discontinue. If you do not want to receive certain types of treatment, or you wish to name someone to make health care decisions for you, you have the right to make these desires known to your doctor, hospital, or other health care providers, and in general, have these rights respected. You also have the right to be told about the nature of your illness in terms that you can understand, the general nature of the proposed treatments, the risks of failing to undergo these treatments and any alternative treatments or procedures that may be available to you.

However, there may be times when you cannot make your wishes known to your doctor or other health care providers. For example, if you were taken to a hospital in a coma, would you want the hospital's medical staff to know what your specific wishes are about the medical care that you want or do not want to receive.

This booklet describes what Massachusetts and federal law have to say about your rights to inform your health care providers about medical care and treatment you want, or do not want, and about your right to select another person to make these decisions for you, if you are physically or mentally unable to make them yourself.

To make these difficult issues easier to understand, we have presented the information in the form of questions and answers. Because this is an important matter, we urge you to talk to your spouse, family, close friends, personal advisor(s), your doctor, and your attorney before deciding whether you want an advance directive.

QUESTIONS AND ANSWERS

GENERAL INFORMATION ABOUT ADVANCE DIRECTIVES

What are "Advance Directives"?

Advance directives are documents which state your choices about medical treatment, or name someone to make decisions about your medical treatment, if you are unable to make these decisions or choices yourself. They are called "advance" directives; because they are signed in advance to let your doctor and other health care providers know your wishes concerning medical treatment. Through advance directives, you can make legally valid decisions about your future medical care. Massachusetts law recognizes only 1 type of advance directives:

1) A Health Care Proxy.

Do I have to have an Advance Directive?

No, it is entirely up to you whether you want to prepare any documents. But if questions arise about the kind of medical treatment that you want or do not want, advance directives may help to solve these important issues. Your doctor or any health care provider cannot require you to have an advance directive in order to receive care; nor can they prohibit you from having an advance directive. Moreover, under Massachusetts law, no health care provider or insurer can charge a different fee or rate depending on whether or not you have executed an advance directive.

What will happen if I do not make an Advance Directive?

You will receive medical care even if you do not have any advance directives. However, there is a greater chance that you will receive more treatment or more procedures than you may want.

If you cannot speak for yourself, and have not made an advance directive, your doctor or other health care providers will generally look to your family or friends for decisions about your care. But if your doctor or your health care facility is unsure, or if your family members cannot agree, they may have to ask the court to appoint a person (called a guardian) to make those decisions for you.

How do I know what treatment I want?

Your doctor must tell you about your medical condition and what different treatments can do for you. Many treatments have serious side effects. Your doctor must give you information, in language that you can understand, about serious problems that medical treatment is likely to cause. Often, more than one treatment might help you, and different people might have different ideas on which is best. Your doctor can tell you the treatments that are available to you, but he cannot choose for you. That choice depends on what is important to you.

Whom should I talk to about Advance Directives?

Before writing down your instructions, you should talk to those people closest to you, and who are concerned about your care and feelings. Discuss them with your family, your doctor, friends, and other appropriate people, such as a member of your clergy, or your lawyer. These are the people who will be involved with your health care, if you are unable to make your own decisions.

When do Advance Directives go into effect?

It is important to remember that these directives only take effect when you can no longer make your own health care decisions. As long as you are able to give "informed consent," your health care providers will rely on YOU, and NOT on your advance directives.

What is Informed Consent?

Informed consent means that you are able to understand the nature, extent and probable consequences of proposed medical treatments and are able to make rational evaluations of the risks and benefits of those treatments as compared with the risks and benefits of alternate procedures, AND you are able to communicate that understanding in any way.

How will my health care providers know if I have any Advance Directives? Doctors, hospitals, and other health care providers must ask you if you have an advance directive(s), and if so, they must see that it is made part of your medical records.

Will my Advance Directives be followed?

Generally, yes, if they comply with Massachusetts law. Federal law requires your health care providers to give you their written policies concerning advance directives. It may happen that your doctor or other health care provider cannot or will not follow your advance directives for moral, religious, or professional reasons, even though they comply with Massachusetts law. If this happens, they must immediately tell you. Then they must also help you transfer to another doctor or facility that will do what you want.

Can I change my mind after I write an Advance Directive?

Yes, at any time, you can cancel or change any advance directive that you have written. To cancel your directive, simply destroy the original document, and tell your family, friends, doctor and anyone else who has copies that you have canceled them. To change your advance directives, simply write and date a new one. Again, give copies of your revised documents to all the appropriate parties, including your doctor.

Do I need a lawyer to help me make an Advance Directive?

A lawyer may be helpful, and you might choose to discuss these matters with him, but there is no legal requirement in Massachusetts to do so. You may use the form that is provided in this booklet to execute your advance directive.

Will my Massachusetts Advance Directive be honored in another state?

The laws on advance directives differ from state to state, so it is unclear whether or not a Massachusetts advance directive will be valid in another state. Because an advance directive is a clear expression of your wishes about medical care, it will influence that care no matter where you are admitted. However, if you plan to spend a great deal of time in another state, you might want to consider signing an advance directive that meets all the legal requirements of that state.

Will my Advance Directive from another state be honored in Massachusetts? Yes. A Health Care Proxy, Durable Power of Attorney for Health Care, or similar document executed in compliance with the laws of another state will be honored in Massachusetts to the extent permitted by Massachusetts law.

What should I do with my Advance Directives?

You should keep them in a safe place where your family members can get to them. Do NOT keep the original copies in your safe deposit box. Give copies of these documents to as many of the following people as you are comfortable with: your spouse and other family members; your doctor; your lawyer; your clergy person; and any local hospital or nursing home where you may be residing. Another idea is to keep a small wallet card in your purse or wallet which states that you have an advance directive and who should be contacted. A wallet card is provided for you at the back of this booklet for that purpose.

HEALTH CARE PROXY

What is a Health Care Proxy?

A Health Care Proxy is a legal document which allows you (the "patient") to appoint another person (the ~ or "agent") to make medical decisions for you if you should become temporarily or permanently unable to make those decisions yourself. The person you choose as your attorney-in-fact does not have to be a lawyer.

Who can I select to be my Agent?

You can appoint almost any adult to be your agent. You should select a person(s) knowledgeable about your wishes, values, religious beliefs, in whom you have trust and confidence, and who knows how you feel about health care. You should discuss the matter with the person(s) you have chosen and make sure that they understand and agree to accept the responsibility.

You can select a member of your family, such as your spouse, child brother or sister, or a close friend. If you select your spouse, and the marriage is dissolved or annulled, the Health Care Proxy is revoked. The following people CANNOT be appointed as your agent:

An owner, operator or employee of a health care facility in which you are a patient or a resident (or have applied for admission), unless that person is related to you by blood, marriage, or adoption. Although it is not illegal to do so, it is usually not a good idea to appoint your attending physician or his/her employees as your agent. This is due to a possible conflict of interest between being your agent and having a direct bearing on the kind of health care you will or will not receive. If you appoint your attending physician, some other physician will have to determine whether you are capable of making your own health care decisions.

The Proxy goes into effect when 1) your doctor has a copy of it, and 2) your doctor has determined that you are temporarily or permanently unable to make your own health care decisions, and 3) your agent consents to start making those decisions.

Remember, as long as you are able to make your own treatment decisions, you have the right to do so.

What decisions can my Agent make?

Unless you limit his/her authority in the Health Care Proxy, your agent will be able to make almost every treatment decision in accordance with accepted medical practice that you could make if you were able to do so. If your wishes are not known or cannot be determined, your agent has the duty to act in your best interest in the performance of his/her duties. These decisions can include authorizing, refusing, or withdrawing treatment, even if it means that you will die. As you can see, the appointment of an agent is a very serious decision on your part.

Can there be more than one Agent?

Yes. While you are not required to do so, you may designate an alternate agent who may also act for you, if your primary agent is unavailable, unable, or unwilling to act. Your alternate has the same decision-making powers as the primary agent.

Can my Agent(s) resign?

Yes. Your agent and your alternate can resign at anytime by giving written notice to you, your doctor or the hospital or nursing home where you are receiving care.

Does my Agent(s) have to accept the appointment in writing?

No, there is no legal requirement for your agent(s) to accept the appointment in writing, but it a good idea. The Health Care Proxy document included in this book contains a section where your agent(s) can formally accept the appointment.

Does the Health Care Proxy have to be signed and witnessed?

Yes, you must sign (or have someone sign the Proxy in your presence and at your direction, if you are unable to sign), and date it. Then it must be witnessed by 2 qualified adult people.

The following people CANNOT act as witnesses:

- 1) The person you appointed as your agent; or
- 2) The person you appointed as your alternate agent.

Does the Health Care Proxy have to be notarized?

There is no legal requirement in Massachusetts to have the document notarized. But several states require their advance directives to be notarized. If you want to ensure that your Health Care Proxy will be valid in other states, having signature and your witnesses' signatures notarized is a good idea.

a Health Care Proxy the same as a "Living Will"?

No, a living will is usually a document that tells your doctor and health care providers whether or not you do want to have life-sustaining treatments or procedures administered to you if you are in a terminal condition or in a persistent vegetative state. It usually does not appoint any individual to make sure the terms of the living will are carried out.

On the other hand, the Health Care Proxy allows you to appoint someone to make health care decisions for you if you cannot make them for yourself. It covers almost all health care decisions, and not just ones that relate to life-sustaining treatments. It also allows you to give specific instructions to your agent about the care you would want or not want to receive.

The Health Care Proxy allows your agent to respond to medical situations that you might not have anticipated and to make decisions for you with knowledge of your values and wishes. Most living wills do not allow you to do this.

What are "life-sustaining" procedures?

These are treatments or procedures that are not expected to cure your terminal condition, or make you better. They only prolong dying. Examples are mechanical respirators which help you breathe, kidney dialysis which clears your body of wastes, and cardiopulmonary resuscitation (CPR) which restores your heartbeat.

What is a "terminal" condition?

A terminal condition is defined as an incurable or irreversible condition for which the administration of medical treatment will only prolong the dying process, and without the administration of these treatments or procedures, death will occur in a relatively short period of time.

What is a "persistent-vegetative" state?

A persistent vegetative state means that a patient is in a permanent coma or state of unconsciousness, caused by illness, injury, or disease. The patient is totally unaware of himself, his surroundings and environment, and to a reasonable degree of medical certainty, there can be no recovery.

Is a "Living Will" valid in Massachusetts?

Massachusetts is one of only 3 states that does not have a specific living will law. However, there are court decisions (Brophy V. New England Sanai Hospital, Inc.) which tend to support the fact that a living will may be recognized in Massachusetts. Since there is no specific statute, we have not included a sample living will document in this booklet. It is suggested that you see your attorney if you wish to execute a Massachusetts living will.

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dba Professional Media Resources
P0 Box 46C380
St Louis. MO 63146~7380
800~753-4251

SUGGESTED READINGS

HEALTH CARE PROXY/LIFE SUSTAINING TREATMENT

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LEGAL GUARDIANSHIP

FULL PERMANENT GUARDIANSHIP - A full, permanent guardian is authorized to make decisions for an individual in both personal and financial matters. The guardian would assume responsibility for any legal contracts the person is involved in, may choose a place of residence or type of treatment or educational program for the person, make decisions regarding major expenditures and decide whether to accept or refuse routine medical treatments. This type of guardianship, however, does not limit an individual's right to make day to day decisions regarding basic choices and preferences. It also does not prevent a person from marrying, making a will or voting. In all cases, the guardian's decisions should try to parallel what that person would want if he or she was able to make the decisions.

PERMANENT LIMITED GUARDIANSHIP - This type of guardianship is generally limited to personal decisions of the individual (not financial) and is often further limited to only medical decisions that the individual would need to make (often referred to as medical guardianship). This type of guardianship is beneficial for those individuals who are able to competently make most of their own life decisions, but need assistance in a particular area (e.g. with medical treatment decisions).

CONSERVATORSHIP - This type of guardian handles the financial affairs of an individual. The individual continues to handle his or her own personal affairs.

TEMPORARY GUARDIANSHIP - This type of guardianship is limited to 90 days. It is typically sought out when a specific medical procedure requires informed consent that a person is unable to provide.

ROGER'S MONITOR - A Roger's Monitor is a person appointed by the court specifically for the purpose of monitoring treatment with anti-psychotic medication. The monitor will oversee an anti-psychotic medication treatment plan for an individual that has been approved by the court.

The court requires that several legal standards be met prior to appointing guardianship. A medical doctor and licensed psychologist must assess the individual, diagnosing disabling conditions and evaluating behavior. A social worker then assesses the person's ability to care for his or her self and the potential for harm if a guardian was not appointed. All evaluations are required to determine if any less restrictive alternative is possible, such as conservatorship, a representative payee, or a citizen advocate.

Family members are often sought out to assume guardianship roles. For individuals who have no actively involved family but have been determined to need a legal guardian, the DMR Service Coordinator will initiate a search to locate a potential guardian. This might be the nearest living relative, a friend or advocate. All living family members will be notified when someone is petitioning for guardianship.

In emergency situations, a temporary guardian can be appointed quickly to make decisions on behalf of the individual. This emergency need for guardianship is usually related to medical needs (e.g. necessary surgery, medication, etc.). Once again, the point of referral is through the DMR Service Coordinator.

Guardians are appointed to assist individuals who are unable to make complex decisions regarding major aspects of their lives. Even when an individual has a guardian to make such decisions, the individual choices that a person makes should be respected and valued (e.g., day to day preferences, relationship choices, etc.). If a conflict or discrepancy between a person and his or her guardian should arise, a proactive role is recommended in helping both parties reach a mutually acceptable resolution.

Massachusetts Network of Information Providers Fact Sheet

From: CN=Vorderer/O=MNIP **Composed By:** Lee Vorderer / 04/27/95 **Updated:** 05/22/95

Category: Disabilities/Illnesses

Key Words: developmental disability

Developmental Disabilities...

What is it?: People with developmental disabilities may have one or more of a wide range of diagnoses or conditions. Many conditions can be developmental disabilities if the onset is early and the disability severe enough to interfere with several major life functions. Section 102(5) of the federal Developmental Disabilities Act (P.L. 101-496) defines the term developmental disability as: "a severe, chronic disability of a person 5 years of age or older which:

- a) is attributable to a mental or physical impairment or combination of mental and physical impairments;
- b) is manifested before the person attains age 22;
- c) is likely to continue indefinitely;
- d) results in substantial functional limitations in three or more of the following areas of major life activity:
 - 1) self care
 - 2) receptive and expressive language
 - 3) learning
 - 4) mobility
 - 5) self-direction
 - 6) capacity for independent living
 - 7) economic self sufficiency; and
- e) reflect the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment or other services which are of lifelong or extended duration and are individually planned and coordinated; except that such term, when applied to infants and young children, means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided."

What are the Effects?: Having a developmental disability affects each individual in a unique way. For some people with developmental disabilities, receiving appropriate services specific to a disability means that their lives are relatively unaffected by the disability. For other individuals, much time is spent addressing issues raised by having a disability. Many individuals with developmental disabilities find assistive technology offers ways to move beyond the disability or compensates for areas affected by the disability. Many people with developmental disabilities hold regular jobs, have families, and participate fully in their home communities. Others with developmental disabilities remain out of the mainstream of society.

What are the Causes?: Developmental disabilities may be caused by accident, either at birth or during early childhood, by a genetic disorder, or by an error in development of a particular system (e.g., neurological development). For approximately half of individuals with developmental disabilities, the cause of the disability is unknown.

Are there Different Types?: The term "developmental disability" includes a wide range of disabilities

and conditions. Examples are autism, cerebral palsy, seizures, head injury, mental retardation, chronic mental illness, deafness, and blindness. Essentially, a developmental disability is defined not by the name of the specific disability, but by the definition of its impact of the individual's life. (See definition, above.)

How many people are Involved?: Based on figures from the 1990 U.S. census and on an estimated 1.5% prevalence rate of developmental disability (Henney and Boggs), there are approximately 90,246 people with developmental disabilities living in Massachusetts.

Can it be Cured or Prevented?: Since some of the causes of developmental disabilities are known, in some cases developmental disabilities can be prevented. Refraining from substance abuse during pregnancy, insuring against ingestion of lead paint by young children, and using appropriate child restraint systems in vehicles can help to prevent certain developmental disabilities. According to the federal Department of Health and Human Services, poverty is one of a complex set of conditions that may predispose a young child to developmental problems.

Can it be Treated?: People with developmental disabilities can receive a range of appropriate treatments to assist them in developing skills and to compensate for areas of disability. Early intervention programs are designed to help young children and their families develop their fullest potential. Special education services, as well as services through regular public schools, assist school-aged children in obtaining relevant, appropriate educations. A range of services for adults with developmental disabilities, including employment assistance, residential and personal supports, transportation, and assistive technology (across the entire age span) offers the opportunity for a full, productive, satisfying life.

Is Research being done?: There is research in progress all over the country and the world on various aspects of developmental disability. Treatment, prevention, and service provision are all areas of focus. For specific information about research on particular disabilities, contact the national association for that disability. For information about general research on developmental disabilities, contact the state or national developmental disability organizations.

Associations/Groups: There are many organizations established to assist people with developmental disabilities and their families. As a result of the federal Developmental Disabilities Act, re-authorized in 1990, each state has a planning council, a protection & advocacy organization, and at least one University Affiliated Program. All are focused on the needs of individuals with developmental disabilities. In addition, there are many disability specific organizations providing info, advocacy and, in some cases, direct services to people with developmental disabilities. Associations for Retarded Citizens, United Cerebral Palsy Associations, and Head Injury Associations are examples of such organizations.

Other Information: For more info re: developmental disabilities, contact:

Massachusetts Developmental Disabilities Council
174 Portland Street, 5th Floor
Boston, MA 02114
(617) 727-6374 (voice)
(617) 727-1885 (TTY)

National Association of Developmental Disabilities Councils (NADD)
1234 Massachusetts Avenue, N.W., Suite 103
Washington, D.C. 20005.

Federal Administration on Developmental Disabilities
Hubert Humphrey Building, Room 336D
200 Independence Avenue, S.W.
Washington D.C. 20201.

Disclaimer: The Massachusetts Network of Information Providers for People with Disabilities (MNIP) is pleased to be able to provide this information. **Please Note:** Information in this fact sheet is provided *as a service*. It is not comprehensive, nor does it take the place of legal advice. The user is encouraged to check references for resources provided, and to keep in mind that the names of providers or additional sources of further information are intended as referrals only; no endorsement by MNIP or this agency should be inferred.

Any information you may provide to update or further complete this fact sheet would be appreciated. Please contact us with changes. We appreciate your help.

Massachusetts Network of Information Providers Fact Sheet

From: Vorderer/MNIP Composed By: Gayle Lopez / 03/31/95 Updated: 05/18/95
Category: Disabilities/Illnesses
Key Words: PDD (Pervasive Developmental Delay / Disability), Hyperactivity, Learning Disability, Kanner's Syndrome, Fragile X Syndrome, Asperger's Syndrome

Autism...

What is it?: Autism is a neurological disorder that affects brain function. It is diagnosed as a developmental disability that affects communication and behavior, usually appearing within the first three years of life, and lasting a lifetime. Autism's characteristic symptoms may range from mild to severe, and may change as an individual grows older. Autism can also occur with other disorders such as epilepsy and mental retardation.

What are the Effects?: Autism is a syndrome that is best described as a variety of impaired and inconsistent communication and behavior characteristics. Such characteristics may manifest themselves in just a few behaviors, or in a combination of several behavioral and/or communication impairments.

Communication impairments may include a loss of speech around eighteen months of age. Speech may or may not return. Some individuals are delayed in speech development (e.g., may mix up the content of words). Some individuals may have echolalia (repeating the words of others), may sing instead of talk, or may talk backwards. Although an individual with autism may or may not be able to speak, s/he is usually unable to communicate effectively to others.

Some behaviors typical of people with autism include playing alone for long periods, twirling a string, avoiding eye contact, rocking and hand flicking. Individuals with autism may also resist cuddling loved ones, and may exhibit tantrums. Such individuals may also be resistant to changes in daily activities, to routines like changing clothes, and/or to a change in the weather. Other characteristics may include a lack of cognitive skills (e.g., learning the alphabet), or the display of normal or superior skills in music, statistics or puzzles. Individuals with autism may also be hypersensitive or insensitive to a normal range of pain, sound, light, touch, taste, or smells.

What are the Causes?: Since autism is not a disease but a neurological disorder which affects certain centers of the brain, it does not have one common cause. However, medical researchers differ about the exact cause or causes of autism. Multiple known causes of autism have been documented in children whose mothers had rubella, CMV (cytomeglovirus), or were exposed to harmful chemicals during pregnancy. Severe infections during early infancy have also been documented to cause autism. An important point of note is that it has been proven there is no known psychological cause (e.g., due to parenting problems) as had been previously thought and published.

Are there Different Types?: Autism is generally classified on a scale of mild to severe. A mild case can resemble a learning disability. In a more severe case (approximately 3%), an individual may show extreme forms of self injurious, repetitive, and/or aggressive behavior.

How many people are Involved?: Statistics show that autism affects approximately five of every 10,000 births. It is three times more common in males than in females, and it can affect any family regardless of race, socioeconomic background, or country of origin. It is the fourth most prevalent developmental disability affecting people today. More people, either undiagnosed or misdiagnosed, may be affected with autism.

Can it be Cured or Prevented?: Currently, researchers do not know specifically what causes autism, so there is no known cure or prevention.

Can it be Treated?: Yes. Through highly structured, skill oriented educational programs, diet, and/or medication, great improvement in day to day activities has been shown by individuals with autism. Educational programs that use highly structured behavior modification protocols, and that are individually tailored in skills training, have been shown to work well for many individuals.

Other techniques include facilitated communication (a facilitator assists the "speaker's" hand, arm, or elbow when s/he types or points to letters) and auditory training (used primarily with those individuals who are hypersensitive to sounds) to try to "draw out" any ability to verbally communicate. Regulating imbalances in nutrition through an increase or avoidance of foods that might trigger symptoms has often been beneficial as well. There is current research on the effectiveness of vitamin and mineral therapy to help improve behavior. Also, medication has been shown to decrease specific symptoms. Finally, parent support groups and counseling for family members have been very helpful in providing continuing education and research on autism.

Is Research being done?: The National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) has conducted research in an effort to identify predictive signs of autism. Additionally, the Autism Research Institute (ARI) has continued the attempt to improve methods of diagnosing, treating, and preventing autism. ARI also has a data bank of information to help parents and professionals keep current on the latest findings on autism. ARI can be reached at (619) 281-7165.

Associations/Groups: For info on diet, current research and support, parents and professionals may write or call the following organizations:

Institute for Child Behavior Research
4182 Adams Avenue
San Diego, CA 92116
(619) 281-7165

Autism Support Center
64 Holten Street
Danvers, MA 01923
(508) 777-9135

Beach Center on Families & Disabilities
University of Kansas
Institute for Life Span Studies
3111 Haworth Hall
Lawrence, KS 66045
(913) 864-7600

- Massachusetts State
Autism Society
148 Linden St. Suite 202
Wellesley, MA 02181
Ms. Julia Barker
Home: (617) 423-3838

TEACCH (Treatment & Education of Autistic &
Related Communication Handicapped Children)
Division of the Department of Psychiatry
School of Medicine
CB 7180, 310 Medical School Wing E
Chapel Hill, NC 27599-7180
(919) 966-2173

Autism Society of America
7910 Woodmont Avenue
Suite 650
Bethesda, MD 20814
800-328-8476

National Autism Hotline
605 9th Street, Prichard Building
PO Box 507
Huntington, WV 25710
304-525-8026

Other Information: Information for this fact sheet was obtained from:

"Fact Sheet: Autism," Office of Scientific and Health Reports, National Institute of Neurological and Communicative Disorders and Stroke, Bethesda, MD, 1991.

"General Information on Autism," Autism Society of America, Bethesda, MD, 1991.

"Autism: Definitions Past and Present," by Ruth C. Sullivan, Autism Services Center, Huntington, WV, 1994.

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Massachusetts Network of Information Providers Fact Sheet

Category: Disabilities/Illnesses

Key Words: retardation, MR, cognitive disability, retarded

Mental Retardation...

What is it?: According to the new definition published in 1992 by the American Association on Mental Retardation (AAMR), mental retardation (MR) is based on three criteria:

- 1) an individual has an intellectual function level (IQ) below 70-75
- 2) an individual has significant limitations in two or more adaptive skill areas
- 3) and the condition is present before the age of 18. (AAMR, 1992).

Adaptive skills are those daily living skills needed to live, work and play in the community: communication, self-care, home living, social skills, leisure, health and safety, functional academics self-direction, community use and work. The new definition looks at the intensity and pattern of supports needed by an individual over time.

What are the Effects?: These vary among people, just as the range of abilities varies among people who do not have mental retardation. Almost 90% will be mildly affected and will be only a little slower than average in learning new information and skills. Most often, these children are unidentified until they enter school. As adults, most will be able to lead independent lives in the community and will no longer be seen as having mental retardation.

The remaining percentage of people will have significant difficulty in learning. However, with early intervention, a focus on what is functional in education, and with appropriate supports as adults, all can lead satisfying lives as contributing citizens.

What are the Causes?: Mental retardation can be caused by any of many conditions that impair the development of the brain before or during birth, or during the childhood years. Hundreds of specific causes have been discovered, but for about one third of the people with mental retardation, the cause is unknown. Among the most common causes of serious mental retardation are Down syndrome, fetal alcohol syndrome and Fragile X syndrome. The causes of mental retardation can be categorized as follows:

Genetic conditions, resulting from an abnormality of genes inherited from the parents or from new mutations in genes in the egg or sperm. In this category are inborn errors of metabolism, like phenylketonuria (PKU) and chromosomal abnormalities (e.g., Down syndrome), which produce mental retardation.

Problems during pregnancy, resulting from use of alcohol or drugs by the pregnant mother, illness of the mother, malnutrition, or glandular disorders. Physical malformations of the brain and HIV infection originating in prenatal life may also result in mental retardation.

Problems at birth, like anoxia, prematurity or low birth weight, may predict MR.

Problems after birth, including childhood diseases that may lead to brain damage; accidents like blows to the head or near drowning; environmental deprivation; & exposure to substances like lead and mercury, can cause injury to the brain and nervous system, resulting in MR.

Are there Different Types?: For the most part, MR is thought of in terms of its effect on the individual

involved. Because of the new definition, the field is moving away from classifications of severity like profound, severe, moderate and mild. Instead, types of MR are being thought of as related to the level of support required by the individual:

intermittent support on an "as needed" basis, rather than constant support and supervision
limited support is needed for a limited period

extensive support is necessary on a daily basis in one or more life areas and that support is probably not time limited

pervasive support which is required in all life areas at all times.

How many people are Involved?: Various studies have been done in local communities to determine the prevalence of MR. These studies have been reviewed by the national advocacy organization that addresses mental retardation (The Arc), and concludes that 2.5 to 3 percent of the general population has mental retardation. Based on the 1990 census, it is estimated that between 6.2 and 7.5 million people have mental retardation.

Can it be Cured or Prevented?: Mental retardation can not be "cured", although appropriate services can help the individual with mental retardation become a contributing member of his or her community. Prevention is possible in many cases because of prenatal and newborn screening strategies and dietary management, as well as various medical management strategies, including those for Rh disease and rubella. Pregnant women can also avoid environmental hazards (e.g. drugs, alcohol, tobacco) to the developing fetus and can secure comprehensive prenatal care.

Can it be Treated?: New attempts at treatment of a variety of causes are being developed, including managing head trauma, asphyxia, and infectious disease. Appropriate services offer individuals with mental retardation opportunities to grow and develop. Early intervention can give infants and toddlers real assistance with development, and school programs can assist people with mental retardation in developing functional skills. Various supports, in home life and work, as well as leisure and recreation, can enable people with mental retardation to make choices about their own lives and be good friends, neighbors and employees.

Is Research being done?: Yes. Research is widespread into the causes of mental retardation, as well as into new treatment and support protocols. Current information can be obtained from the Arc (see below).

Associations/Groups: Many groups provide information and support for individuals with mental retardation and their families, as well as to people who provide services to those with mental retardation. (The following are statewide or national organizations, but many cities and towns have local Arcs. These can be located by calling the Mass Chapter office.) These include:

The Arc, National Headquarters
Post Office Box 1047
Arlington, Texas 76004
817-261-6003
817-277-0553 (TTY)

The Arc/Massachusetts Chapter
217 South Street
Waltham, MA 02154
617-891-6270

The President's Committee on Mental Retardation
330 Independence Avenue, SW
Washington, DC 20201
202-619-0634

The Mental Retardation Providers' Council
217 South Street
Waltham, MA 02154
617-891-7327

The Massachusetts Department of Mental Retardation
160 North Washington Street
Boston, MA 02114
617-727-5608 (ask the operator to give you the phone number for your local Area Office)

Other Information: References used for this fact sheet include:

The Arc/US Home Page on the Internet (<http://TheArc.org/faqs/mrqa.html>)

AAMR (1992). **Mental Retardation: Definition, Classification, and System of Supports**, 9th Ed.

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Massachusetts Network of Information Providers Fact Sheet

Category: Disabilities/Illnesses

Key Words: Cerebral Palsy

Cerebral Palsy...

What is it?: Cerebral Palsy (CP) is a term used to describe a group of chronic conditions affecting body movement and muscle coordination. CP is caused by damage to one or more specific areas of the brain, usually occurring during fetal development; before, during or shortly following birth; or during infancy. "Cerebral" refers to the brain and "palsy" to muscle weakness/poor control. CP itself is not progressive (i.e., it does not get worse); however, secondary conditions can develop which may, over time, get worse, get better, or remain the same. CP is not communicable. It is not a disease and should never be referred to as such. Although CP is not "curable" in the accepted sense, training and therapy can help improve function.

What are the Effects?: CP is characterized by an inability to fully control motor function, particularly muscle control and coordination. Depending on which areas of the brain have been damaged, one or more of the following may occur: muscle tightness or spasm; involuntary movement; disturbance in gait and mobility; abnormal sensation and perception; impairment of sight, hearing or speech; seizures; and mental retardation. Because of these, other problems may arise, such as difficulties in feeding, bladder and bowel control, problems and breathing because of postural difficulties, skin disorders because of pressure sores, and learning disabilities.

What are the Causes?: Any damage to the brain, whether caused by genetic or developmental-mental disorders, injury or disease, may produce CP. One important cause is an insufficient amount of oxygen reaching the fetal or newborn brain. Oxygen supply can be interrupted by premature separation of the placenta from the wall of the uterus, awkward birth position of the baby, labor that is too long or too abrupt, or interference with circulation in the umbilical cord. Premature birth, low birth weight, Rh or A-O-B blood type incompatibility between mother and infant, infection of the mother with German measles or other virus diseases in early pregnancy, and microorganisms that attack the infant's central nervous system are also risk factors for CP. Most causes of CP are related to developmental and childbearing processes and, since the condition is not inherited, it is often called congenital cerebral palsy. A less common type is acquired cerebral palsy. Head injury is the most frequent cause, and is usually the result of motor vehicle accidents, falls, child abuse, or brain infection.

Are there Different Types?: There are three main types: spastic -- stiff and difficult movement; athetoid -- involuntary and uncontrolled movement; ataxic -- disturbed sense of balance and depth perception. There may be a mixture of these types for any individual. Other types do occur, although infrequently.

How many people are Involved?: It is estimated that some 500,000 children and adults in the United States manifest one or more of the symptoms of CP. Currently, about 5,000 babies and infants are diagnosed with the condition each year and, in addition, some 1,200 - 1,500 preschool age children acquire CP annually.

Can it be Cured or Prevented?: Yes. Measures of prevention are increasingly possible today. Pregnant women are tested routinely for the Rh factor. If Rh negative, they can be immunized within 72 hours after the birth (or after the pregnancy terminates) and thereby prevent adverse consequences of blood incompatibility in a subsequent pregnancy. If a woman has not been immunized, the consequences of blood incompatibility in the newborn can be prevented by exchange transfusion in the

baby. If the newborn baby has jaundice, s/he can be treated by phototherapy in the hospital nursery. Other preventive programs are directed toward reducing exposure of pregnant women to virus and to other infections; unnecessary exposure to X-rays, to drugs and to medications; and the control of diabetes, anemia and other nutritional deficiencies. Of great importance are optimal well-being prior to conception, adequate prenatal care, and protecting children from accidents or injury.

Can it be Treated?: "Management" is a better word than "treatment." Management consists of helping the child achieve maximum potential in growth and development. This should be started as early as possible with identification of the very young child who may have a developmental disorder. A management program can then be started promptly to include attention to the child's movement, learning, speech, hearing, and social and emotional development. In these programs, physicians, therapists, educators, nurses, social workers, and other professionals assist the family as well as the child. Certain medications, surgery, and braces may be used to improve nerve and muscle coordination, and prevent dysfunction.

As individuals mature, they may require support services essential to the developing adult, such as personal assistance services, continuing therapy, educational and vocational training, independent living services, counseling, transportation, recreation/leisure programs, and employment opportunities. People with CP can go to school, have jobs, get married, raise families, and live in homes of their own. Most of all, people with CP need the opportunity for full inclusion in our society.

Is Research being done?: Yes. Active national programs of research are being vigorously pursued to prevent CP and to improve the quality of life for persons with CP. The two organizations with major research programs are the United Cerebral Research and Educational Foundation in the private sector, and the National Institutes of Health in the government sector. The research questions being addressed include:

- o What are the factors that predispose the developing fetal brain to injury? Can these factors be eliminated or minimized?
- o What are the causes of lack of oxygen to the developing fetal brain? Can the developing fetal and newborn brain be protected against these factors?
- o Why is low birth weight in the full term infant an important risk factor for CP?
- o Can CP be diagnosed before birth, and better diagnosed shortly after birth?
- o Which available treatments are the most effective for specific disabilities of persons with CP?
- o Based on new knowledge now available in the medical, surgical, behavioral and bioengineering sciences, what improvements can be made in the quality of life of people with CP?
- o What are the effects of aging on the person with CP?

Associations/Groups: United Cerebral Palsy Associations, Inc. is a nationwide network of approximately 155 state and local voluntary agencies (UCP affiliates) which provides services and conducts public and professional education programs relevant to CP. Direct services provided by UCP affiliates to children and adults with CP and their families include medical diagnosis, evaluation and treatment; information and referral; early intervention; employment; individual and family support; social and recreation programs; community inclusion and independent living; advocacy and community education. In the December, 1992 issue of MONEY magazine, UCPA was rated the number one health care organization, with over 86 percent of its funds going to programs and services.

Other Information: This fact sheet is from UCPA, December, 1993

United Cerebral Palsy Associations, Inc.
1522 K Street, NW, Suite 1112
Washington, DC 20005-1202
800-872-5827 voice/TDD 202-842-1266

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Massachusetts Network of Information Providers Fact Sheet

Category: Disabilities/Illnesses

Key Words: Epilepsy, Seizures, Seizure Disorder

Epilepsy...

What is it?: Epilepsy (the susceptibility to recurring seizures) is a complicated neurological disorder produced by sudden brief changes in the electrical function of the brain. In epilepsy, the pattern of nerve cell (neuron) activity is disrupted. When nerve cells are not working properly, a person's consciousness, movements or actions may be altered for a short time. These physical changes are seizures.

What are the Effects?: Epilepsy is a chronic condition that requires a lifetime of continual medical treatment and education. Currently, there is no cure for epilepsy. Major problems associated with the disorder include:

Treatment - Despite available therapies, an estimated 15% of people with epilepsy do not have complete seizure control, and a similar proportion of cases are virtually resistant to current drug therapy. New medications with fewer side effects are desperately needed, both for cases resistant to treatment, and for patients under multiple drug therapy for whom monotherapy is not yet possible.

Diagnosis - There are more than 20 different seizure disorders. Now permitting the more specific diagnosis and treatment of epilepsy are the following factors: recent international reclassification of symptoms, improved brain wave monitoring technology, new and efficient methods to precisely measure blood drug levels, and non-invasive brain imaging and brain function measurement technologies. Convulsive seizures are easily recognized. But there are other, less apparent forms of epilepsy marked by non-convulsive seizure types. These seizures affect awareness, produce brief loss of muscle control and may involve sensory distortions. Early diagnosis is crucial. Children and adults with undiagnosed seizures risk developing a more severe, more difficult to treat condition.

Unemployment/Underemployment - 20% to 30% of people with epilepsy, who are physically able to work, are unemployed. Many of those who are employed have been forced to accept positions far below their ability and educational achievement. For many people, having epilepsy has been less of a problem than overcoming negative attitudes about their intellectual and physical abilities. Changes in the law, especially the provisions of the Americans with Disabilities Act, offer new hope in this area.

Impact on Children - The National Center for Health Statistics reports 422,000 cases of epilepsy in children 18 years of age and under, based on the 1988 National Health Interview Survey. Of these children, 65.5%, or 276,500, have special needs ("a condition that caused problems during the past year, such as missing school, staying in bed or feeling upset most or all of the time").

Mortality - Epilepsy carries an increased risk of death from a variety of causes. Most seizures are benign, but a prolonged seizure can evolve into status epilepticus, a condition that sometimes leads to brain damage and, occasionally, to death. People with epilepsy also have a greater than average fatality rate for suicide; sudden unexplained death syndrome; and accidental death, especially drowning.

What are the Causes?: In about 70% of cases, there is no known cause. Of the remaining 30%, the following are most frequent:

Head trauma, especially from automobile accidents, gunshot wounds, sports accidents, falls and blows at work or in the home. The more severe the injury, the greater the risk of developing epilepsy.

Brain tumor and stroke.

Poisoning, such as lead poisoning. More than 5,000 persons each year are reported to suffer seizures caused by alcoholism.

Infection - meningitis, viral encephalitis, lupus erythematosus and, less frequently, mumps, measles, diphtheria and others.

Maternal injury, infection or systemic illness affecting the developing brain of the fetus during pregnancy.

Role of heredity: All people inherit varying degrees of susceptibility to seizures. The genetic factor is assumed to be greater when no specific cause can be identified.

Are there Different Types?: See chart on page 4.

How many people are Involved?: Approximately 2,500,000 people in the U.S. have some form of epilepsy. Although anyone can develop epilepsy at anytime, it primarily affects children and young adults. Twenty percent of cases develop before the age of five. Fifty percent develop before the age of 25. Epilepsy is also increasingly associated with the elderly. There are as many cases of epilepsy in those 60 years of age and older as in children 10 years of age and younger. A large number of children and adults have undetected or untreated epilepsy. About 125,000 newly diagnosed cases occur each year.

Can it be Cured or Prevented?: Epilepsy can often be prevented through appropriate safety measures that protect the development of the brain and injury to it. Appropriate prenatal care and prevention of head injury help to reduce the incidence of epilepsy.

Can it be Treated?: Modern treatment methods can achieve full or partial control of seizures in about 85% of cases. Some seizure disorders of infancy and early childhood are still highly resistant to current therapies.

Medical --- major form of treatment is long-term anticonvulsant drug therapy. Some 20 antiepileptic drugs are currently in use. While multiple drug therapy is sometimes necessary, single drug therapy is more common.

Surgical ---- used only when medication fails. Most common form takes place when the brain tissue causing seizures is confined to a small focal area of the brain which can be safely removed without damaging personality or function.

Dietary ---- a special high fat, high calorie diet may succeed in some childhood cases when standard treatment fails.

Is Research being done?: EAM believes that, through research advances, we will prevent and one day cure epilepsy and its complications, improving the quality of life of millions of individuals and saving billions of dollars. The investment that the federal government and private industry have made in epilepsy research over the past few decades has led to many advances in treatment. New and better anti-seizure medications and surgical techniques are improving seizure control, and have enabled many people with epilepsy to lead independent and productive lives.

In 1993 and 1994, the FDA approved two new drugs for the treatment of seizures -- gabapentin and lamotrigine. These drugs are a major addition to the treatment arsenal for various seizure types. They will benefit many adults and children who continue to have uncontrolled seizures, or who are experiencing debilitating side effects from their current medication.

Presently, epilepsy research at the National Institute for Neurological Disorders and Stroke (NINDS), an institute of the National Institutes of Health, focuses on why neurons in the brain become seizure prone, how such neurons are able to recruit neighboring cells in spreading abnormal discharges, and what can be done about it. Basic research and clinical research have benefited from many new tools (e.g., magnetic resonance imaging) and techniques (e.g., intensive video EEG monitoring) that have emerged within the last decade. Other recent breakthroughs include: identification of the gene for juvenile myoclonic epilepsy (a form of epilepsy that typically begins in adolescence); and an understanding of how epileptic seizure sites develop (which may help explain the mechanism of seizure generation and clarify steps to improved therapy).

However, more research focusing on children and adults with intractable epilepsy is needed. For example, basic molecular neurobiology research being developed in several areas may lead to a whole new generation of more effective and less toxic anti-seizure medications. Another area ripe for research is women and epilepsy. Among the areas where further research is needed is the relationship between hormones and seizures throughout the female life cycle, and the pregnancy risks for women with epilepsy.

In 1993, the Centers for Disease Control and Prevention (CDC) launched its epilepsy program within the National Center for Chronic Disease Prevention and Health Promotion. This program focuses on early detection and treatment of epilepsy, and on enhancing the overall quality of life of persons with epilepsy, by targeting its outreach and education efforts to consumers and health professionals. Areas of program emphasis include the importance of early and accurate diagnosis, appropriate treatment, prevention of unnecessary death and injury and patient education and management.

There are currently two studies underway. One deals with direct medical costs and a second deals with assessment of the effectiveness of prevention and education intervention. The CDC is also creating a database dedicated to specifically capturing information on prevention, intervention, and education activities. The Epilepsy Foundation of America, the American Epilepsy Society and the National Association of Epilepsy Centers have been working with the CDC in planning and developing these initiatives.

Associations/Groups: For further information, please write to the Epilepsy Foundation of America, 4351 Garden City Drive, Landover, MD 20785, or call them at 1-800-332-4050 or (301) 459-3700.

Other Information: For more information contact the Epilepsy Association of Massachusetts at (617) 542-2292.

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Massachusetts Network of Information Providers Fact Sheet

Category: Disabilities/Illnesses

Key Words: Hearing and vision loss, Multi-sensorily impaired, Usher Syndrome, Deaf-Blindness

Deaf-Blindness...

What is it?: Deaf-blindness is a combined loss of hearing and vision, whether from birth (congenital) or from an onset later in life (adventitious). Illness, trauma, and/or age are the leading causes of deaf-blindness. Many people who are born deaf-blind may have additional disabilities such as developmental delays or mental retardation. However, deaf-blindness does not necessarily entail total hearing and vision loss or developmental delays.

What are the Effects?: Deaf-blindness can greatly interfere with a person's ability to effectively function in the world.. Physically, an individual with deaf-blindness experiences loss of sight and sound, and thus must deal with adjustments of moving about. Being restricted in mobility can mean physical isolation from people. Socially, a loss of hearing and vision may affect how an individual learns to communicate with others using both expressive and receptive skills. For example, if a person is born with deaf-blindness, someone must deliberately expose and encourage him/her to learn to communicate with others. This can be done through family members, through therapists, and through special education programs. If hearing and vision are lost gradually or suddenly, an individual may be able to continue to express him/herself through speech or through sign language. An individual may also learn to use other methods of expressive or receptive skills. Emotionally, these individuals may experience feelings of frustration, isolation, loneliness, rejection, or of any variety of other feelings that may come with a gradual or sudden loss of sound and sight.

What are the Causes?: Anyone can develop deaf-blindness at any age. The leading causes of deaf-blindness are Usher Syndrome, maternal rubella syndrome, bacterial meningitis, and viral infections including CMV (cytomegavirus). Usher Syndrome is a hereditary condition causing hearing loss at birth, then a progressive vision loss known as retinitis pigmentosa (a degeneration of the retina causing night blindness and tunnel vision and sometimes total blindness). Maternal rubella syndrome (German measles) is caused by a virus that may be carried by a pregnant woman, affecting the fetus in utero. This is a leading cause of hearing and vision loss in children. Other conditions that can cause deaf-blindness are aging (cataracts, glaucoma, diabetic retinopathy); trauma; accident or injury to the head, ears and eyes; and the use of certain medications that have been linked to deaf-blindness such as chemotherapy, or ototoxic or ear damaging drugs.

Are there Different Types?: There is no single way to categorize an individual with deaf-blindness because the type and degree of hearing and vision loss can vary widely. Most people with deaf-blindness fall into one of the following categories: those who are (1) both deaf and blind from birth or early childhood; (2) blind from birth or early childhood and lose hearing in adult life; (3) deaf from birth or early childhood and lose vision in adult life; or (4) those who lose both vision and hearing in adult life. There are two types of the most prevalent cause of deaf-blindness: Usher Syndrome type I and type II. In Usher syndrome type I, the individual is usually born deaf and, beginning as early as childhood, may experience progressive vision loss accompanied by problems with balance. In Usher Syndrome type II, the individual is usually born hard-of-hearing, experiences the same kind of vision loss as type I, but usually in adulthood and without balancing problems.

How many people are Involved?: It has been estimated that approximately 40,000 individuals in the United States have been diagnosed with deaf-blindness to some degree. Deaf-blindness affects approximately three in 100,000 births. Also some 6,000 children were born deaf-blind and with other

disabilities during the 1963-65 rubella (German measles) outbreak.

Can it be Cured or Prevented?: No.

Can it be Treated?: The effects of deaf-blindness can be treated through a variety of educational, vocational, and technological advances. The major focus of treatment is to teach methods of communication and independent mobility. Educational interventions may include learning or relearning how to communicate with others by reading and writing in Braille, by using large print books, by finger spelling, by printing on the palm of the hand, or by learning American Sign Language (ASL).

Also, technology has aided individuals with deaf-blindness to communicate through devices such as: the Tellatouch (portable, it permits a person to type a message on a regular keyboard while the person who is deaf-blind receives the message on a Braille cell), the Optacon (a reader that converts an image of a printed letter into a vibrating tactile form felt with one finger), or a TTY (teletype machine). Other technology includes closed caption television, personal paging systems, household devices that vibrate, word processing systems, laptop computers, and portable note taking machines.

Mobility is also an issue for persons with deaf-blindness who may need assistance in getting around more independently. To help increase mobility, for instance, a person with deaf-blindness may 1) learn to walk with a cane, a guide person, or a guide dog; 2) use adapted private or public buses or vans, and/or; 3) use specially designed index cards to show to the general public for directions or for questions.

Is Research being done?: The Helen Keller National Center conducts research to develop sensory aids and specialized techniques to help diminish the impairing effects of deaf-blindness. The Center provides support, research, and conferences for the development of improved services for people with deaf-blindness. Research is also being conducted to find the cause of Usher Syndrome and to find how this genetic disorder affects vision and hearing.

Associations/Groups:

Helen Keller National Center for Deaf-blind Youths and Adults
111 Middle Neck Road
Sands Point, NY 11050-1299
(516) 944-8900 (voice)
(516) 944-8637 (TTY)
(516) 944-7302 (fax)

National Family Association for Deaf-blind
c/o Helen Keller National Center
111 Middle Neck Road
Sands Point, NY 11050-1299
(800) 255-0411 ext. 275

American Association of Deaf-blind
814 Thayer Avenue, Room 300
Silver Spring, MD 20901
(301) 588-6545 (voice)
(301) 523-1265 (TTY)

DB-LINK - National Info Clearinghouse on Children who are Deaf-blind
Central Office
Teaching Research
345 N. Monmouth Avenue
Monmouth, OR 97361
(800) 438-9376 (voice)

(800) 854-7013 (TTY)
(503) 838-8150 (fax)

Other Information: Info for this fact sheet was obtained from:

"Without Sight and Sound: Facts about Deaf-blindness," Helen Keller National Center, Sands Point, NY, 1994.

"Deaf-blindness: A Fact Sheet," Hearing-Vision Impaired Program in Adult and Continuing Education, College for Continuing Education, Gallaudet University Press, 800 Florida Ave, NE, Washington, D.C. 20002-3695, 1994.

"Being in Touch - Communication and Other Issues in the Lives of People who are Deaf-blind," College for Continuing Education, Gallaudet University Press, Washington, D. C., 1994.

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HORACE MANN EDUCATIONAL ASSOCIATES, INC.

PERSONAL HEALTH FACT SHEET

Completed by _____ Date _____

Name _____ DOB _____ HT _____ WT _____

Address _____ Phone _____

Allergies _____ Insurance _____

_____ Social
_____ Security # _____

Tetanus _____ TB _____ Hepatitis Status _____

Emergency Contact Person: _____ Current Medications (Dose & Frequency) _____

Name _____

Relationship _____

Phone _____

Guardian:

Name _____

Address _____

Phone _____

Health Care Proxy:

Name _____

Address _____

Phone _____

Rogers Guardian:

Name _____

Address _____

Phone _____

Current Medical Problems:

Primary Care Physician:

Name _____

Address _____

Phone _____

Pharmacy:

Name _____

Phone _____

Past Medications:

DMR Service Coordinator:

Name _____

Address _____

Phone _____

Contact

Person

Day Program:

Name _____

Phone _____

Current Diagnosis:

Former Conditions, Hospitalizations & Surgeries:

SPECIAL HEALTH CONCERNS IN PERSONS WITH DOWN SYNDROME

CONCERN	CLINICAL EXPRESSION	WHEN SEEN	PREVALENCE	MANAGEMENT
CONGENITAL HEART DISEASE	ENDOCARDIAL CUSHION DEFECT, VENTRICULAR SEPTAL DEFECT, TETRALOGY OF FALLOT	NEWBORN OR FIRST YEAR	34%	ECG, CHEST X RAY, CARDIAC CONSULTATION, SURGICAL REPAIR
HYPOTONIA	REDUCED MUSCLE TONE, INCREASED RANGE OF JOINTS, MOTOR FUNCTION PROBLEMS	THROUGHOUT, IMPROVEMENT WITH MATURITY	ALL	GUIDANCE BY PHYSICAL THERAPY, EARLY INTERVENTION
DELAYED GROWTH	TYPICALLY AT OR NEAR THIRD PERCENTILE	THROUGHOUT	ALL	EARLY NUTRITIONAL SUPPORT; CHECK HEART
DEVELOPMENTAL DELAYS	SOME GLOBAL DELAY, VARIABLE DEGREES, SPECIAL LANGUAGE PROBLEMS	1ST YR; CONTINUES	ALL	EARLY INTERVENTION, SPECIAL EDUCATION, LANGUAGE THERAPY
HEARING PROBLEMS	SEROUS OTITIS MEDIA, SMALL EAR CANALS, CONDUCTIVE IMPAIRMENT	CHECK BY 1 YR; REVIEW REGULARLY	70%	AUDIOLOGY, TYMPANOMETRY, ENT CONSULTATION
OCULAR PROBLEMS	REFRACTIVE ERRORS, STRABISMUS, CATARACTS	EYE EXAM BY 1 YR., THEN FOLLOW UPS	50%, 35%, 15%	OPHTHALMOLOGIC CONSULTATION
CERVICAL SPINE ABNORMALITY	ATLANTOAXIAL INSTABILITY, POTENTIAL LONG-TRACK SIGNS	XRAY BY 3 YR; OCCASIONAL REPEAT	10% +/-, 1%-2%	ORTHOPEDIC NEUROLOGIC HELP; POSSIBLE RESTRICTION, FUSION
THYROID DISEASE	HYPOTHYROIDISM (RARE HYPER=), DECREASED GROWTH	SOME CONGENITAL/ MOST 2ND + DECADE; CHECK 2 YR, REPEAT	15%	REPLACEMENT THERAPY AS NEEDED
OBESITY	EXCESSIVE WEIGHT GAIN	2-3 YR, 12-13 YR, AND IN ADULT LIFE	COMMON	CALORIC RESTRICTION ACTIVITY
SEIZURE DISORDERS	PRIMARY GENERALIZED (ALSO HYP SAR-RHYTHMIA)	ANY TIME	5%-10%	USUAL MANAGEMENT
EMOTIONAL PROBLEMS	INAPPROPRIATE BEHAVIOR, DEPRESSION, OTHER EMOTIONAL DISTURBANCES	MID TO LATE CHILDHOOD, ADULT LIFE	COMMON	MENTAL HEALTH ASSISTANCE, FAMILY GUIDANCE
PREMATURE SENESCENCE	BEHAVIORAL CHANGES, FUNCTIONAL LOSSES	4TH, 5TH DECADES	UNKNOWN (INCREASED RATE)	SPECIAL SUPPORT

STATES Table 7

People per Thousand Who Had a Self Care or Mobility Difficulty, 1990

STATE	AGE 16 TO 64			AGE 65 AND OVER		
	TOTAL POP	SELF CARE (per 1,000)	MOBILITY (per 1,000)	TOTAL POP	SELF CARE (per 1,000)	MOBILITY (per 1,000)
Alabama	2,530,000	47	30	500,000	159	212
Alaska	343,000	18	13	21,000	91	130
Arizona	2,256,000	30	20	463,000	93	130
Arkansas	1,426,000	39	29	330,000	143	191
California	19,164,000	38	21	2,986,000	116	147
Colorado	2,134,000	23	16	311,000	94	136
Connecticut	2,137,000	29	16	417,000	115	137
Delaware	429,000	33	20	77,000	107	145
District of Columbia	411,000	59	26	72,000	146	170
Florida	7,810,000	37	24	2,292,000	112	133
Georgia	4,161,000	40	25	620,000	144	198
Hawaii	673,000	32	16	121,000	111	126
Idaho	599,000	18	16	115,000	79	123
Illinois	7,262,000	35	21	1,351,000	118	155
Indiana	3,510,000	31	20	650,000	112	153
Iowa	1,691,000	23	16	392,000	103	128
Kansas	1,495,000	26	16	318,000	99	132
Kentucky	2,321,000	37	33	442,000	139	207
Louisiana	2,582,000	47	30	439,000	153	198
Maine	773,000	24	20	154,000	99	145
Maryland	3,137,000	37	19	491,000	117	157
Massachusetts	3,945,000	27	20	767,000	112	146
Michigan	5,925,000	33	23	1,055,000	117	159
Minnesota	2,753,000	20	14	504,000	95	125
Mississippi	1,558,000	53	34	307,000	169	222
Missouri	3,172,000	31	22	671,000	122	161

Montana	485,000	20	16	99,000	78	119
Nebraska	950,000	21	14	205,000	86	116
Nevada	788,000	29	19	124,000	97	125
New Hampshire	726,000	19	15	117,000	95	131
New Jersey	5,030,000	37	20	985,000	119	148
New Mexico	928,000	34	23	157,000	107	149
New York	11,656,000	45	25	2,239,000	132	158
North Carolina	4,244,000	38	24	761,000	137	186
North Dakota	377,000	16	13	83,000	75	105
Ohio	6,861,000	32	23	1,321,000	116	158
Oklahoma	1,923,000	31	25	397,000	125	172
Oregon	1,781,000	23	18	375,000	96	133
Pennsylvania	7,474,000	32	22	1,729,000	119	153
Rhode Island	639,000	30	21	141,000	115	143
South Carolina	2,183,000	48	27	380,000	141	184
South Dakota	404,000	21	16	94,000	69	105
Tennessee	3,123,000	35	28	586,000	138	197
Texas	10,696,000	34	21	1,616,000	131	171
Utah	991,000	19	14	144,000	92	137
Vermont	366,000	16	15	62,000	82	131
Virginia	3,967,000	31	20	627,000	123	169
Washington	3,077,000	22	18	546,000	94	131
West Virginia	1,127,000	39	36	258,000	144	209
Wisconsin	3,054,000	22	17	605,000	97	125
Wyoming	279,000	16	12	44,000	82	121

NOTE: Rate per thousand people is reported in the Self Care and Mobility columns. Total number of people with Self Care or Mobility difficulty may be calculated by multiplying the rate by the number of thousands of people in the Total Population. For example, the number of people age 16 to 64 in Alabama who had Self Care difficulty was 2,530 (the number of thousands in the Total Population) multiplied by 47 (the rate per thousand) which equals 118,910.

SOURCE: U.S. Bureau of the Census, 1990 Census. From a report by LaPlante, M.P. Disability Statistics Report 3: State Estimates of Disability in America, National Institute on Disability and Rehabilitation Research.

States Table 8

Children Age 6 to 21 with Specific Learning Disabilities (SLD), Speech or Language Impairments (SLI), Mental Retardation (MR), Serious Emotional Disturbance (SED), Hearing Impairments (HI), and Orthopedic Impairments (OI) Served under Chapter 1 and The Individuals with Disabilities Education Act (IDEA, Part B), 1993-94

STATE	ALL DIS	SLD	SLI	MR	SED	HI	OI
Alabama	90,599	38,230	17,438	24,849	5,614	949	471
Alaska	15,373	9,638	3,251	613	801	185	96
Arizona	61,845	36,222	11,681	5,594	4,022	1,178	748
Arkansas	46,215	25,818	6,718	10,447	355	527	160
California	481,746	294,554	105,924	26,554	15,636	7,860	9,406
Colorado	59,584	33,399	88,793	2,744	8,483	912	1,703
Connecticut	63,988	33,775	10,536	4,011	11,068	723	249
Delaware	13,243	8,291	1,587	1,634	903	189	332
District of Columbia	6,394	3,802	353	1,172	762	27	72
Florida	258,522	118,655	69,577	30,380	29,918	1,868	4,399
Georgia	111,274	36,126	24,021	24,999	21,568	1,247	753
Hawaii	13,358	7,276	2,186	1,563	1,257	302	157
Idaho	19,882	11,895	3,424	2,767	416	299	155
Illinois	227,640	115,588	54,479	23,037	25,877	2,797	2,490
Indiana	115,087	49,068	34,453	19,636	7,179	1,341	768
Iowa	56,740	26,682	8,585	11,220	7,447	788	983
Kansas	44,017	19,740	10,332	5,264	4,590	550	468
Kentucky	66,871	22,927	18,348	18,132	3,957	793	399
Louisiana	75,848	34,467	16,788	11,948	5,313	1,335	1,204
Maine	26,477	12,283	6,012	1,466	4,096	263	138
Maryland	85,980	42,903	23,377	5,455	5,594	1,152	533
Massachusetts	139,112	85,103	21,412	13,572	11,857	1,315	849
Michigan	161,503	78,069	34,249	19,057	17,336	2,551	5,885
Minnesota	78,193	34,165	13,493	9,728	15,235	1,577	1,245
Mississippi	58,257	30,958	17,490	7,277	251	546	1,115
Missouri	104,900	56,106	23,148	12,303	9,085	1,039	704
Montana	16,270	9,900	3,159	1,196	976	231	68

Nebraska	33,384	14,883	8,375	4,836	2,712	602	500
Nevada	22,027	13,774	4,286	1,405	1,237	215	166
New Hampshire	20,793	11,653	4,385	846	1,937	229	163
New Jersey	171,978	93,566	47,005	4,638	13,818	1,263	503
New Mexico	39,843	20,287	11,535	1,895	3,444	419	481
New York	319,454	187,210	35,039	19,227	44,098	5,641	3,031
North Carolina	121,471	54,971	25,252	22,401	9,697	1,868	926
North Dakota	11,104	5,616	3,150	1,253	554	107	107
Ohio	203,528	77,875	50,885	45,617	10,579	2,280	2,258
Oklahoma	66,503	34,826	14,232	11,873	2,265	699	327
Oregon	57,353	30,270	13,213	4,388	3,687	1,537	1,055
Pennsylvania	186,578	88,442	43,034	29,096	17,492	2,911	1,195
Rhode Island	20,784	13,148	3,716	1,044	1,790	153	177
South Carolina	71,359	30,691	17,823	14,780	5,048	942	731
South Dakota	13,389	6,809	3,519	1,408	604	168	128
Tennessee	107,347	56,896	24,396	13,170	3,370	1,320	1,091
Texas	373,858	222,432	64,330	24,034	32,129	5,015	4,301
Utah	46,694	26,324	7,582	3,342	5,958	654	203
Vermont	9,220	4,338	1,816	1,271	1,103	144	85
Virginia	117,328	60,652	24,994	13,166	10,669	1,202	750
Washington	86,862	41,126	15,801	7,610	5,535	2,404	1,167
West Virginia	39,230	17,977	10,640	7,280	2,015	374	263
Wisconsin	86,764	28,718	16,009	4,582	12,643	359	645
Wyoming	10,569	5,546	2,859	636	735	160	166
Puerto Rico	39,196	14,477	2,885	16,287	976	900	586
American Samoa	386	113	132	88	21	11	2
Guam	1,591	1,055	212	164	20	33	20
Northern Marianas	362	218	24	14	6	8	20
Palau	420	265	15	26	31	34	11
Virgin Islands	1,325	435	134	608	26	17	1
Bur. of Indian Affairs	6,447	3,787	1,287	389	484	36	7
U.S. & Outlying Areas	4,786,065	2,444,020	1,009,379	553,992	414,279	64,249	56,616
50 States, D.C. & P.R.	4,775,534	2,438,147	1,007,575	552,703	413,691	64,110	56,555

NOTE: Totals may be used to compute percentages (e.g., $38,230/90,599 = 0.422 = 42.2\% =$ percent served in Alabama with Specific Learning Disabilities, SLD).

SOURCE: U.S. Department of Education, Annual Report to Congress on the Implementation of The Individuals with Disabilities Education Act.

States Table 9

Children Age 6 to 21 with Visual Impairments (VI), Autism (A), Deaf-Blindness (DB), Traumatic Brain Injury (TBI), Multiple Disabilities (MD), Other Health Impairments (OHI) Served under Chapter 1 and The Individuals with Disabilities Education Act (IDEA, Part B), 1993-94

STATE	ALL DIS	VI	A	DB	TBI	MD	OHI
Alabama	90,599	436	169	12	121	1,310	1,000
Alaska	15,373	43	28	14	30	470	204
Arizona	61,845	408	249	9	102	1,237	395
Arkansas	46,215	181	88	7	69	788	1,057
California	481,746	3,129	1,912	157	371	5,407	10,836
Colorado	59,584	304	32	60	78	3,076	0
Connecticut	63,988	464	236	26	55	1,473	1,372
Delaware	13,243	92	135	75	5	0	0
District of Columbia	6,394	39	46	10	1	10	100
Florida	258,522	1,127	914	23	20	0	1,641
Georgia	111,274	513	266	30	86	0	1,665
Hawaii	13,358	64	64	1	6	209	273
Idaho	19,882	79	61	8	78	331	369
Illinois	227,640	1,070	457	36	81	0	1,728
Indiana	115,087	592	453	61	192	848	496
Iowa	56,740	184	162	38	57	593	1
Kansas	44,017	193	147	7	159	1,529	1,038
Kentucky	66,871	481	75	4	71	1,178	506
Louisiana	75,848	461	527	11	61	862	2,871
Maine	26,477	91	80	7	51	1,419	571
Maryland	85,980	469	191	38	106	4,426	1,736
Massachusetts	139,112	588	550	38	280	2,423	1,125
Michigan	161,503	819	1,388	0	0	2,149	0
Minnesota	78,193	352	401	23	76	0	1,898
Mississippi	58,257	214	16	14	8	368	0
Missouri	104,900	369	399	77	136	539	995
Montana	16,270	80	41	23	51	224	321
Nebraska	33,384	208	37	3	62	381	785

Nevada	22,027	90	42	0	21	327	464
New Hampshire	20,793	91	0	4	0	321	1,164
New Jersey	171,978	346	659	36	37	9,521	586
New Mexico	39,843	146	39	12	85	908	592
New York	319,454	1,651	2,248	71	276	15,198	5,764
North Carolina	121,471	611	917	14	78	1,321	3,415
North Dakota	11,104	54	27	50	17	0	169
Ohio	203,528	978	136	16	69	10,677	2,158
Oklahoma	66,503	294	89	30	75	1,391	402
Oregon	57,353	542	1,051	16	132	0	1,462
Pennsylvania	186,578	1,322	816	2	1,300	804	164
Rhode Island	20,784	78	28	5	23	164	458
South Carolina	71,359	384	155	20	32	334	419
South Dakota	13,389	67	43	9	31	472	131
Tennessee	107,347	849	374	14	114	1,764	3,989
Texas	373,858	1,959	1,750	62	130	3,016	14,700
Utah	46,694	332	139	49	183	1,440	488
Vermont	9,220	36	28	1	15	94	289
Virginia	117,328	501	629	1	82	2,944	1,738
Washington	86,862	327	51	26	36	3,037	9,742
West Virginia	39,230	223	155	24	54	0	225
Wisconsin	86,764	272	23	4	31	22,944	534
Wyoming	10,569	51	17	0	40	0	359
Puerto Rico	39,196	619	353	37	17	1,276	783
American Samoa	386	2	0	3	1	13	0
Guam	1,591	15	2	3	2	36	29
Northern Marianas	362	0	6	2	0	62	2
Palau	420	26	0	3	0	4	5
Virgin Islands	1,325	2	1	45	0	42	14
Bur. of Indian Affairs	6,447	17	1	1	1	386	51
U.S. & Outlying Areas	4,786,065	24,935	18,903	1,372	5,295	109,746	83,279
50 States, D.C. & P.R.	4,775,534	24,873	18,893	1,315	5,291	109,203	83,178

NOTE: Totals may be used to compute percentages (e.g., $436/90,599 = 0.005 = 0.5\%$ = percent served in Alabama with Visual Impairments, VI).

SOURCE: U.S. Department of Education, Annual Report to Congress on the Implementation of The Individuals with Disabilities Education Act.

TERMINOLOGY

1. **Terminal illness** - An illness with no known cure that will cause a person to die.
2. **Life sustaining treatment** - Treatment used to keep person alive by artificial means.
3. **Coma** - A state of prolonged unconsciousness in which the eyes remain closed and there is no distinction in apparent waking and sleep conditions. Apparent awareness and wakefulness are both absent.
4. **Persistent vegetative state** - The patient is completely unaware of his/her self or surroundings. She/he does not experience body cues such as pain or hunger. There may be sleep-wake cycles and eye or body movement.
A thoughtful and careful diagnosis is required to determine persistent vegetative state.

While in a persistent vegetative state, a person is:

- a. Unable to change position. Must be turned frequently.
- b. Unable to eat. Fed by a tube.
- c. Incontinent of urine and feces.
- d. Possibly on a ventilator.
- e. Unaware of people visiting.
- f. Prone to pneumonia, bed sores, muscle contractures.

5. **Death** - Cessation of cardiac function.
6. **Brain Death** - Total cessation of integrated brain function.
May be declared for those people on life sustaining machines.
 - a. **Criteria:**
The following must be absent for at least 12 hrs.
 1. Pupil reflexes
 2. Jaw reflex
 3. Gag reflex
 4. Response to noxious stimuli
 5. Spontaneous respiratory movement with oxygen and vent. disconnected for 10 min.
 6. No electrical brain activity by EEG for 30 minutes.

7. **Palliative Care** - Relieving or alleviating symptoms without curing.

TERMINOLOGY

8. Hospice - Specialized palliative care of patients with terminal illness.
Usually covers the last 6 months of life.
 - A. Factors that help estimate life span.
 1. Disease progression.
 2. If cancer, type of tumor, extent of metastases (spread to another site).
 3. Emotional and physical withdrawal.
 4. Reduced level of nutrition.
 5. Progression of symptoms.
 - B. Emphasis may include:
 1. Relief of pain.
 - a. Drugs (do not worry about addiction).
 - b. Radiation Therapy (very effective in bone cancer).
 - c. Surgery, i.e., relief of bowel obstruction not related to the disease or repair of fractures related to injury.
 - d. Antibiotics, if appropriate.
 2. Relief of other symptoms, i.e.
 - a. Nausea.
 - b. Constipation.
 - c. Anxiety.
 - d. Depression.
 - C. Types of treatment discouraged:
 1. Artificial nutrition and hydration. (A natural part of the dying process is the decreased intake of food and fluids).
 2. Chemotherapy should be completed before hospice admission.
 - a. Deemed no longer effective.
 - b. Patient refuses further treatment.
 - D. Hospice care may be provided in the home, hospital, cancer center or ~~free~~ standing hospice facility.

Hospice expertise may be provided by members of a team consisting of physician(s), nurse, social worker, volunteer, chaplin and pharmacist. Family and friends are a part of the process and need continued support during all phases of care and during period of bereavement.

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U.S. Table 1

People with Disabilities, 1991-92

EVERYBODY IN THE U.S.		
	PEOPLE	PERCENT
Total population in the U.S.	251,796,000	100.0
Total people in the U.S. with a disability	48,936,000	19.4
Total people in the U.S. with a severe disability	24,117,000	9.6
Total people in the U.S. with a non-severe disability	24,819,000	9.9
PEOPLE AGE 0 TO 14 IN THE U.S.		
	PEOPLE	PERCENT
Total population of the U.S. age 0 to 14	56,067,000	100.0
People age 0 to 14 with a disability	2,913,000	5.2
People age 0 to 14 with a severe disability	529,000	0.9
People age 0 to 14 with a non-severe disability	2,384,000	4.3
PEOPLE AGE 15 AND OVER IN THE U.S.		
	PEOPLE	PERCENT
Total population of the U.S. age 15 and over	195,729,000	100.0
People age 15 and over with a disability	46,023,000	23.5
People age 15 and over with a severe disability	23,588,000	12.1
People age 15 and over with a non-severe disability	22,435,000	11.5

NOTE: Disability (for people age 15 and over) was defined as (a) used a wheelchair, (b) had used a cane or similar aid for six months or longer, (c) had difficulty with a functional activity, (d) had difficulty with an activity of daily living, (e) had difficulty with an instrumental activity, or (f) had a developmental disability or a mental or emotional disability. Severe Disability was defined as (a) being unable to perform one or more of the defined Activities, or (b) as having one or more of the defined Impairments, or (c) as a person who used a wheelchair or who was a long-term user of crutches, a cane, or a walker. The 17 Activities may be found listed in a separate Table. For people age 0 to 14, disability was defined based on responses of parents/guardians about limitations in usual activities, receipt of developmental services, ability to do regular schoolwork, and ability to walk, run, or use stairs.

SOURCE: U.S. Bureau of the Census, Americans with Disabilities: 1991-92.

